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SHARED DECISION-MAKING IN THE MANAGEMENT OF TYPE 2 DIABETES MELLITUS IN MALAYSIA: AN EXPLORATION OF THE PERSPECTIVE OF PATIENTS AND HEALTHCARE PROFESSIONALS

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Declaration

This is to certify that this thesis has been composed by me, in which it reports my own work. No part of this thesis has been submitted for any other degree or professional qualification.

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Abstract

Background: Decisions regarding the management of Type 2 Diabetes Mellitus (T2DM) are complex as the management of this chronic illness requires a multifaceted approach. Shared decision-making is a patient-centred care approach in which the patients and their healthcare professionals (HCPs) collaboratively make a health decision, not only using the best available evidence, but also reflecting patients' needs, preferences and values. While there is growing evidence of the effectiveness of shared decision-making in supporting T2DM patients' involvement in the decisions across the world, potentially contributing to the improvement of their overall well-being, little is actually known about patient involvement in the decisions and particularly about shared decision-making in the Malaysian context.

Aims: This study explores the experiences and perspectives of patients and HCPs on patient involvement in decision-making in the management of T2DM in Malaysia.

Methods: A qualitative research design is employed in this study. Data were collected in the outpatient setting of three health facilities in the urban area of Malaysia. Face-to-face in-depth interviews were conducted, over a period of six months, with 19 HCPs (including three specialists, five medical officers, five diabetes educators/nurses, four dietitians/nutritionist and two pharmacists) and 24 T2DM patients. Thematic analysis and constant comparative method were used to analyse the data.

Findings: The data highlighted a range of interpretations of shared decision-making. While patients described shared decision-making as a way for their concerns, preferences and values to be heard and addressed by their HCPs, the HCPs emphasised their patients' agreement and compliance with their recommendations. The types of decisions made, despite professed patient involvement would seem to remain largely in the hands of the HCPs. The extent to which patients are generally involved is subtle, whereby the decision is not necessarily shared and the decision-making for T2DM extends outside the face-to-face clinical encounter.

This study also highlights that patient involvement in their decision is mainly influenced by patients and HCPs characteristics, values, beliefs, culture and past

experience; their interpersonal relationship and communication; and role expectations in the healthcare field. Using Bourdieu's work to shape analysis showed that these factors intersect with each other and create a multifaceted patient-HCP power dynamic in making the decision. By including different groups of HCPs, this study also has provided valuable insight into the struggle among the non-physicians, who perceived to have limited decision-making power in managing patients with T2DM despite being the HCPs who were found to be more encouraging of patient involvement in the decisions. This is an addition to the struggles that are generally faced by all groups of HCPs, including their dilemma to balance their ethical foundation of beneficence and respecting patients' autonomy; their limited opportunity for involving patients due to constraints on the resources available at their facilities; and the language barrier.

Conclusion: In conclusion, this study highlights the benefit of integrating the shared decision-making approach with some additional emphases on facilitating patient involvement in the decisions. These emphases include (1) inclusion of problem identification as one of the element of shared decision-making; (2) reducing the power gap and struggle by explicitly addressing the power issue and improving patients' cultural health capital; (3) strengthening of patient-HCP interpersonal relationship and communication skills; (4) allowing experimentation of different options that suit patients' condition; (5) integration of other approaches including motivational interviewing, support for self-management and interprofessional collaboration.

Keywords: Shared decision-making, Patient-centred care, Type 2 Diabetes Mellitus, Outpatient setting,

Lay Summary

Shared decision-making has been spreading throughout the world as a patient-centred care approach to help patients to be involved in the decisions during the clinical encounter. In this approach, patients' needs, preferences and values are important in making a decision apart from healthcare professionals' (HCPs') medical expertise, In Malaysia, despite the integration of patient-centred care particularly in Type 2 Diabetes Mellitus (T2DM) as a long-standing illness, little is known about patient involvement in decision-making particularly shared decision-making.

The research aimed to understand the experiences and views of T2DM patients and HCPs regarding patient involvement in decision-making in the management of T2DM in Malaysia. In the course of six months, 19 HCPs (including three specialists, five medical officers, five diabetes educators/nurses, four dietitians/nutritionist and two pharmacists) and 24 T2DM patients from three different clinics in Malaysian urban area were interviewed.

Shared decision-making was interpreted differently between patients and HCPs. While some patients described shared decision-making as a way for their concerns, preferences and values to be heard and addressed by their HCPs, the HCPs emphasised their patients' agreement and compliance with their recommendations. Even though the participants generally claimed that the decisions are shared among patients and HCPs, it seemed to remain largely in the hands of the HCPs. The extent to which patients are generally involved is subtle, whereby the decision is not necessarily shared and the decision-making for T2DM extends outside the face-to-face clinical encounter.

This study also highlights that patient involvement in their decision is mainly influenced by patients and HCPs characteristics, including their values, beliefs, culture and past experience; their interpersonal relationship and communication, and the roles that they are expected to play when they meet each other. These factors found to be interlinked with each other and contribute to a complex patient-HCP power dynamic in making the decisions. By including different groups of HCPs, this study also has found the struggle among the non-physicians, who perceived to have

limited decision-making power in managing patient with T2DM. This is an addition to the struggles that are generally faced by all groups of HCPs, including their dilemma to balance their ethical foundation of doing good for patients and respecting patients' right; their limited opportunity for involving patients due to constraints on the resources available at their facilities; and the language barrier.

In conclusion, this study highlights the benefit of integrating shared decision-making approach with some additional emphases in encouraging patient involvement in the decisions. These emphases include (1) inclusion of problem identification as one of the element of shared decision-making; (2) reducing the power gap and struggle by explicitly addressing the power issue and improving patients' ability to be involved; (3) strengthening the patient-HCP interpersonal relationship and communication skills; (4) allowing the patients to try different options that suit patients' condition; (5) integration of other approaches including motivational interviewing, support for self-management and interprofessional collaboration.

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List of abbreviations

ADA	American Diabetes Association
CADQAS	Computer-Assisted Qualitative Data Analysis Software
CPG	Clinical Practice Guidelines
DMTAC	Diabetes Medicine Therapy Adherence Clinics
DRC	Diabetes Resource Centre
FMS	Family Medicine Specialist
HbA1c	Glycated Haemoglobin
HCP	Healthcare Professionals
IOM	Institute of Medicine
MEMS	Malaysian Endocrine & Metabolic Society
MOH	Ministry of Health
MREC	Medical Research Ethics Committee
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NMRR	National Medical Research Register
RM	Ringgit Malaysia
SMBG	Self-monitoring Blood Glucose
T2DM	Type 2 Diabetes Mellitus
UK	United Kingdom
USA	United States of America
US$	United States Dollar

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Outline of the thesis

This thesis consists of seven chapters. Chapter 1 has outlined the background information about T2DM, shared decision-making, together with Malaysian cultural background and document review regarding patient involvement in decision-making Malaysia, to set the context for this study. Chapter 2 presents an overview of the theoretical context surrounding patient involvement in decision-making and a review of the related empirical studies. These highlight the gap in knowledge and practice to further justified the relevant of this study. Chapter 3 provides details on the study design and methodological approach used in this study. Chapters 4 and 5 present and discuss the findings of the study from the perspective of both patients and HCPs, while Chapter 6 further explores and discusses the key findings of this study. Finally, Chapter 7 summarises the thesis in addition to presenting the implications and recommendations that are drawn.

CHAPTER 1: INTRODUCTION

1.1 Introduction

This chapter introduces the study context in the form of an overview of the Type 2 Diabetes Mellitus (T2DM) epidemic occurring both globally and in Malaysia. This is followed by a discussion of patient empowerment and autonomy as the foundation of patient-centred care in the management of T2DM. Next, there is an overview of shared decision-making as one of the approaches to patient involvement in decision-making. Setting the context for the study, the following section presents an overview of the Malaysian background, including the cultural background and the integration of patient involvement in decision-making in the current Malaysian government documentation.

1.2 Type 2 Diabetes Mellitus (T2DM)

Diabetes is defined as *"... a serious, chronic disease that occurs either when the pancreas does not produce enough insulin (a hormone that regulates body glucose), or when the body cannot effectively use the insulin it produces"* (World Health Organization (WHO), 2016: p. 6). T2DM is the most common form of diabetes, occurring among 90% of the diabetic population, and is a major health issue affecting people worldwide. In 2012, WHO (2014) estimated that a total of 1.5 million deaths could be directly attributed to this non-communicable disease. By 2017, this figure had almost tripled, to 4 million deaths (International Diabetes Federation (IDF), 2017a). The International Diabetes Federation (IDF) (2017a) has also estimated that 80% of the 425 million T2DM cases worldwide occur in low- and middle-income countries. It is considered to be a lifestyle disease despite also being partly affected by genetic disposition (Holman, Young & Gadsby, 2015). In Asia, there were estimated to be 110 million individuals with diabetes in 2007, with this number continuing to rise due mainly to the impacts of economic development, the modification of nutritional intake and the adoption of a sedentary lifestyle (Chan et al., 2009).

As an Asian country, Malaysia is currently grappling with this type of health situation. A series of National Health Morbidity Surveys conducted by the Ministry of Health (MOH) Malaysia revealed a shocking escalation in the prevalence of T2DM among individuals aged 30 years and over, with the number showing an almost twofold increase over a period 15 years, rising from a rate of 8.3% in 1996 to 14.9% in 2006 and, finally, to 20.8% in 2011 (Institute for Public Health, 2011). The same national surveys also reported that the prevalence of T2DM among adults aged 18 and over rose from 11.6% in 2006 to 17.5% in 2015, which is double the estimated prevalence of 8.5% for the South East Asia region in 2017 (Institute for Public Health, 2015; IDF, 2017b). This demonstrates not only the alarming trend of the increase in T2DM in Malaysia but also a phenomenon similar to the surge in early-onset T2DM as seen in the United Kingdom (UK) and United States of America (USA) (Mokdad et al., 2000; Gonzalez, Johansson, Wallander, & Rodriguez, 2009).

Currently, while a large number of T2DM patients are able to endure acute complications of the disease owing to the development of new technologies in the healthcare system, there remains no cure for T2DM, except for the replacement of pancreatic cells (Buse et al., 2009). Thus, the main objective of T2DM management is remission, as opposed to treatment of the disease being curative in nature. T2DM is managed through a combination of lifestyle modifications and pharmacological modalities in the effort to mitigate its symptoms and either prevent or delay chronic complications, which may be macrovascular (amputation, cardiovascular diseases) and/or microvascular (retinopathy, nephropathy) in nature and potentially lead to premature disability and death (Klein, 1995; Stratton, 2000).

T2DM as a chronic illness also demands the long-term active engagement of patients as it requires continuous adjustment, decision-making and self-management. In facilitating its management, the Chronic Care Model (Bodenheimer, Lorig, Holman, & Grumbach, 2002) has been globally accepted. This model advocates the active involvement of patients who must be kept well informed as to their current condition owing to the important role that they themselves play in the management of their

T2DM (Coleman, Austin, Brach & Wagner, 2009). Nonetheless, advances in medical technology and strategy have also provided an array of T2DM management options. It is thus becoming ever more complicated to select the ideal pharmacological therapy and lifestyle modification for patients (Cohen & Shaw, 2007; Nathan, 2015).

Globally, the common aim of T2DM management is to reduce patients' glycaemic level to an optimum level, with the glycated haemoglobin (HbA1c) test being one of the most popular ways of measuring this (National Institute for Health and Care Excellence (NICE), 2015; Malaysian Endocrine & Metabolic Society (MEMS), 2016; American Diabetes Association (ADA), 2017). This is due to its strong association with a reduction in the risk of T2DM complications despite it being incapable of providing glycaemic variability or occurrences of hypoglycaemia, with the latter being one of the dangerous acute complications of T2DM (Duckworth et al., 2009; ADA, 2017). HbA1c is a blood test that reveals the average measures of plasma glucose concentration, with the optimum level varying among countries and patients. According to the ADA (2017), the target HbA1c level should in the range of less than 6.5% to less than 8.0%, dependent on the individual case, while guidelines issued by the UK's NICE (2015) stipulate a target of less than 6.5% to less than 7.0%, with the recommendation to be less stringent in some cases in order to minimise the risk of hypoglycaemia. The Malaysian Clinical Practice Guidelines (MEMS, 2016) resolve with a target optimum range of less than 6.0% to less than 8.0%, depending on the patient's condition.

As a chronic progressive illness, T2DM is considered to be a major health concern due to its negative implications in terms of both the quality of life of the sufferer and also with respect to its impact on national economies (Ibrahim et al., 2010). Patients with T2DM require prolonged and frequent health follow-ups to ensure the delivery of consistent pharmacological and non-pharmacological management. This is crucial for the prevention of acute and chronic multiple-organ T2DM complications. The IDF (2017b) has estimated that global healthcare expenditure on patients with diabetes aged 20–79 rose from 232 billion US dollars (US$) in 2007 to US$ 727

billion in 2017, in parallel with the aforementioned steep rise in the prevalence of T2DM worldwide. Similarly, in response to the massive increase in the prevalence of diabetes in Malaysia, the Malaysian government has allocated a significant proportion of its health budget to improving management of the condition. It is estimated that a total of 2.04 billion Malaysia ringgits (RM) (approx. US$ 521 million) was spent in 2011, while approximately 78% of cases are still considered to be of uncontrolled diabetes (Mafauzy, Hussein, & Chan, 2011; Feisul et al., 2017). Furthermore, T2DM is a chronic disease that requires long-term management, with the majority of this management being carried out in the primary care setting. It is estimated that 60.2% of the total budget is allocated to this setting (Sharifa Ezat, Azimatun, Amrizal Rohaizan, Saperi, 2009).

Overall, T2DM imposes an economic burden not only in terms of direct medical expenditures globally, nationally and personally, but also indirectly due to the frequent disability and early mortality of T2DM patients arising from its increasingly early onset (WHO, 2016). Thus, an exploration of new low-cost approaches to managing patients suffering from this disease, especially in the primary care setting, is needed to facilitate the better achievement of optimal outcomes and to prevent further devastating complications. Globally, the management of T2DM is being strengthened by the integration of patient-centred care. Despite the debate with regard to its cost-effectiveness, this approach is found to contribute positively to patients' experience in managing their health, which then improves their quality of life (Inzucchi, et al., 2012; Slingerland, et al., 2013; Ahmad, Ellins, Krelle & Lawrie, 2014; Zanariah, Sri Wahyu, Singh, 2015). The care required to manage patients' long-term illness is tailored to their personal needs, abilities and values since both patients and healthcare professionals (HCPs) work together to improve patients' health outcomes and quality of life. In doing so, two major components of the concept are emphasised – patient involvement in decision-making and patients' self-management in managing their T2DM.

1.3 Patients' empowerment and autonomy in T2DM

As mentioned in the previous section 1.2, there is great scope for the involvement of T2DM patients in decision-making and self-management, arising from the need for them to continuously adapt to their uncertain health condition as a way of managing the chronic illness. Hence, Anderson and Funnell (2010) emphasised the importance of strengthening patients' autonomy and empowerment so that they are able to play an active role during discussions of their T2DM management and to enable them to effectively carry out their own self-management. Peek and colleagues (2012) demonstrated that a lack of adherence to treatment is often associated with patients' lack of autonomy as it provides a means by which they can express their preferences, especially if they consider their treatment to be not flexible, too limiting or as something that has been chosen for them by a physician. On the other hand, Ahmad and colleagues (2014) found that many patients were keen to become more involved in their healthcare and that patient-centred care in T2DM management has a hugely positive impact on patients' self-efficacy. This then has the effect of further facilitating patients' involvement in decision-making and self-management.

The process of empowering T2DM patients is defined as *"... the discovery and development of one's inherent capacity to be responsible for one's own life"* (Funnell et al., 1991: p. 37). This definition was further elaborated by Funnell and Anderson (2004: p. 124) as *"...a patient-centered, collaborative approach tailored to match the fundamental realities of diabetes care"*. While autonomy *"... encompasses self-rule that is free from both controlling interference by others and limitations that present meaningful choice (such as inadequate understanding)"* (Beauchamp & Childress, 2013, p. 101). The notion of autonomy supports the involvement of patients in their own healthcare management, while HCPs are responsible for explaining in detail the treatment options available. Strengthening patients' autonomy and empowering them to self-manage their health is also pivotal within policymakers' attempts to achieve value for money and may also help in tackling the problem of health inequalities between socio-economic groups (Burchardt et al., 2010).

Patient involvement in the making of health- and medical-related decisions has also been widely encouraged due to the growing recognition of the need for patient autonomy in respect of biomedical ethics. Over the past decade, interest in this ethical principle has surpassed beneficence in the health and medical field due to the strong arguments made by lawyers, judges and medical ethicists regarding patients' right to decide what will be done to their bodies (Moulton & King, 2010). Patient autonomy has gained increasing levels of attention in line with the rise of consumerism, liberalism and individualism, all of which are interrelated within the current broader global socio-economic framework (Macfarlane, 1978; Mohd Darbi, 2006). Autonomy means that T2DM patients have the right to be fully informed regarding their medical or health condition and involved in their own disease management, thus ultimately improving their overall outcomes and reducing medical costs (Flierler, Nübling, Kasper, & Heidegger, 2013; Miller & Jawad, 2014).

Moreover, it is important that the management and treatment options selected are those that are best suited to T2DM patients. This is because treatment modalities will mostly be carried out by the patients themselves, outside of the healthcare system. Certain types of management also require an element of deliberation with patients as they will usually be required to attend a medical appointment to receive them. Patients are supported in becoming involved via the concept of autonomy. It is essential that a patient is both mentally and medically capable of making an autonomous decision since decision-making is an intentional act that needs to be accompanied by a substantial understanding of the existing options and free of any influence from external or internal sources (Beauchamp & Childress, 2013). Autonomous decisions made by patients should not be overridden by HCPs, with the latter being responsible for carrying out the treatment as requested by their patients (Kumarasamy et al., 2014).

However, there is always the potential for an autonomous request or decision made by a patient to contradict the treatment or management option that an HCP believes will be best for him or her. This HCP's recommendation of the option which he or she believes to be the best is reflecting the concept of beneficence. Beneficence is

described by Beauchamp and Childress (2013: p. 203) as *"... a statement of moral obligation to act for the benefit of others"*. Beneficence has commonly been used as the basis of the traditional paternalistic approach, together with the concept of nonmaleficence, which is defined as *"... obligations not to harm others"* (Beauchamp & Childress, 2013: p. 151). The contribution of HCPs to the decision-making process remains crucial as they possess the medical knowledge and skills to help patients better manage their T2DM. Thus, the HCP team require some common ground in order to ensure they are in the best position to respect patients' autonomy while still adhering to the principle of beneficence in relation to their patients' care and striving to improve patient-centred care. Shared decision-making is considered to be the most applicable approach in terms of striking a balance between these two important components of biomedical ethics (Charles, Gafni, & Whelan, 1997) and has been found to have a positive relationship with patient empowerment (Zoffmann, Harder, & Kirkevold, 2008; Varming et al., 2015). Elwyn et al. (2012) further emphasise the relevance of shared decision-making in current health practice due to it being based on the two tenets of self-determination and relational autonomy. They interpret the latter as *"... the term used to describe the view that we are always related to interpersonal relationships and mutual dependencies"* (p. 1362).

1.4 Shared decision-making and T2DM

Patient involvement in decision-making is often referred to as shared decision-making in the existing literature as it describes the optimum balance of combined patient/HCP effort in making decisions (Charles et al., 1997; Lewis-Barned, 2016). Similar to the support given to self-management, shared decision-making has attracted a lot of attention over this 20 years since Charles and colleagues introduced one of the first models in 1997. However, it can also be sensed that the research on shared decision-making in T2DM is not as extensive as that related to support for the self-management of T2DM. This may be due to the common conceptualisation of shared decision-making that it occurs at a specific time, in a certain context and in one-off dyadic encounters, which is in contrast to self-management that is more concerned with the management of a long-term health problem (Charles et al., 1997;

Ahmad et al., 2014;). This therefore adds to the lack of clarity with regard to the shared decision-making approach itself (Clayman & Makoul, 2009).

Nevertheless, since shared decision-making encourages a collaborative patient–HCP effort, it is believed that this approach will enable the team to reach the most suitable decision that has a significant impact in the long run (Montori, Gafni, & Charles, 2006). Shared decision-making also appears to be particularly relevant in the case of T2DM as it may enhance patient empowerment and self-efficacy, enabling them to have better control of their glycaemic level and prevent the development of any complications (Zoffmann et al., 2008; Clark et al., 2009). It may also provide a range of benefits, such as improving patients' knowledge of the disease, reducing their anxiety and stress, improving various health outcomes and reducing the associated range of treatment and cost (Olsson, Jakobsson Ung, Swedberg, & Ekman, 2012; E. O. Lee & Emanuel, 2013; Veroff et al., 2013). Since patients share their initial treatment plan with their HCPs, they also have the opportunity to modify it, notably should they encounter any barriers to or consequences of carrying it out (Montori et al., 2006). For these reasons, shared decision-making has become the current central paradigm in the concept of patient participation and has developed into a contemporary evidence-based approach to managing chronic illness (Deegan & Drake, 2006; Zikmund-Fisher et al., 2010).

1.4.1 Shared decision-making vs self-management in T2DM

Aside from shared decision-making, self-management is another common area of patient-centred care in the management of patients with T2DM. Whether the practice and research of these two important areas of patient-centred care are carried out separately or together, it is undeniable that they are closely related (Ahmad et al., 2014). Ahmad and colleagues (2014: p. 12) define self-management as *"... the behaviours that individuals engage in outside of the health context"*, while self-management support refers to *"... how individuals are supported in their self-management goals and activities by health care professionals (and others)"*. These definitions highlight the difference between shared decision-making and self-management, with shared decision-making relating to how the management decision

(including self-management decision) is reached and requiring an ongoing partnership between patients and HCPs (Montori et al., 2006). Correspondingly, Ahmad and colleagues (2014) suggest that shared decision-making is a component of self-management support.

1.5 Malaysian contextual background

To reiterate, Malaysia, as the setting of this current study, is facing a rapidly growing T2DM epidemic. This section presents the contextual and cultural background in order to set the scene of the study. This is followed by the findings of an analysis of the existing government documentation related to patient involvement in decisions.

Malaysia is a country in South East Asia with an equatorial and tropical climate, being hot and humid throughout the year. It consists of Peninsular Malaysia and East Malaysia and has a total land area of 329,847 km^2. Malaysia became an independent country on 31st August 1957. Prior to gaining its independence from the British Empire, it attracted traders and colonial powers due to its strategic location on the Malay Peninsula straddling East and West, in addition to its natural resources. This contributed to the diversity of ethnicities, cultures and religions currently seen in the country. In 2017, the total population of Malaysia was estimated at 32 million, spread across 14 states. Malays account for 68.8% of the population, Chinese make up 23.2%, Indians 7.0%, while 1% are classed as others (Department of Statistics Malaysia, 2017). The country's official religion is Islam, while other religions, including Buddhism, Hinduism, Christianity and others, are also represented. Malay is the official language and the mother tongue of the Malays, the country's majority ethnic group. Despite this, English is spoken by the majority and is the preferred language, especially in the realm of intercultural interaction.

Since its independence, Malaysia has functioned as a democratic country and adopts a British-style parliamentary system with a prime minister as the head of the government. The government of Malaysia holds federal legislative powers covering

areas including finance, health, defence, education, external affairs, internal security, civil and criminal law, and citizenship. In comparison to the era before the 1970s, when Malaysia's economy was mostly dependent on its raw natural resources, the country nowadays has a diversified economy that ranges from its natural resources to its industrial and manufacturing commodities (The World Bank, 2017). Due to the growth of its economy, Malaysia is today one of the most urbanised developing countries. Its remarkable development has also attracted workers from other countries, contributing to a non-citizen population of 3.3 million (10.3%) (Department of Statistics Malaysia, 2017). This rapid growth is exerting pressure not only on the provision of physical infrastructure in Malaysia but also on the country's health services.

1.5.1 The cultural background of Malaysia

Culture has been defined differently across various fields and throughout time, yet the various definitions share a common basis. One of the earliest and clearest definitions of culture was by Sir Edward Tylor, who described culture as *"… that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society"* (1870: p. 1; cited by Avruch, 1998: p. 6). Hofstede (1993: p. 89) defined it more recently as *"... the collective programming of the mind which distinguishes one group or category of people from another"*. Thus, it can be concluded that different societies have different cultures that are composed of distinct norms and values, and these will manifest in different attitudes, behaviours and practices.

As an Asian country, Malaysia is a collectivist society, characterised by high power distance, a high-context culture and low uncertainty avoidance (Hall, 1976; Hofstede, 1980). Although Hofstede's cultural dimensions are not typically used when discussing culture in medicine and health (Verma, Griffin, Dacre, & Elder, 2016), these dimensions were found to be related to the views and practices of the participants in this current study. This is presented and discussed further in the Findings and Discussion chapters.

Collectivism refers to *"... societies in which people from birth onward are integrated into strong, cohesive in-groups, which throughout people's lifetime continue to protect them in exchange for unquestioning loyalty"* (Hofstede & Hofstede, 2005: p. 76). As a collective society, Malaysia is situated at the opposite end of the spectrum from UK and US, which known as individualist society (Hofstede, 1980). In a collectivist society, and thus including Malaysia, an individual's main concern when making a decision is to ensure that neither the decision nor the process of making it harms their relationship with others (Guess, 2004). This is because they believe that the success of any decision-making depends on them fulfilling their social and cultural expectation. This element is important since they are more dependent on and loyal to their group, in comparison to the individualist (Darwish & Huber, 2003). Consequently, the collectivist tends to compromise with others and is motivated by a desire to maintain social harmony (LeFebvre & Franke, 2013). In contrast, the individualist's primary orientations are to achieve personal justice and autonomy and to uphold the right of the individual, with relatively less in the way of concern for others (Guess, 2004; Darwish & Huber, 2003). As a result, in comparison to the collectivist, the individualist tends to be more confident in their decision-making ability, in addition to being more rational and focused on the task of making the decision itself (Guess, 2004; LeFebvre & Franke, 2013). Despite this, Chen and Li (2005) revealed that the individualism–collectivism cultural spectrum is not at all simple. They investigated the cultural differences in decision-making between collectivists and individualists. They found the collectivists in their study to be less cooperative with other groups of people when making decisions compared to the individualists, which contradicts the values commonly associated with collectivism. However, they also discovered that the collectivists were more cooperative with other groups when they were in a foreign territory. Compared to previous studies, Chen and Li also found that the collectivists were more confident in their judgements, which is parallel to individualism. This is further discussed at the end of this section.

The power distance index is described by Hofstede and Hofstede (2005) as *"... the extent to which the less powerful members of institutions and organizations within a country expect and accept that power is distributed unequally"* (p. 46). Based on a

study by Hofstede (1980), Malaysia has one of the highest power distance values. Power itself is defined as *"... the potential to determine or direct (to a certain extent) the behaviour of another person/other persons more so than the other way round"* (Mulder, 1977: p. 90). Correspondingly, as a country with a high power distance, it is common in Malaysia for hierarchical boundaries to be obvious and for there to be top-down decision-making with little to no discussion as a result of the society's high respect for both hierarchy and the people occupying the upper levels of the hierarchy, who are usually the experts (Abdullah, Hassan, Ali, & Karim, 2014). For the same reason, there is a lack of interest in becoming involved in arguments with the experts, thereby leading to a reluctance to question, refuse or disagree with them (Jung & Kellaris, 2006). This contrasts with people in societies where there is low power distance who typically view everyone as being somewhat equal. In terms of communicating information, Pornpitakpan and Francis (2000) found that, in contrast to a society with lower power distance, which focuses on the evidence provided, a society with high power distance places a high value on the credibility of the source of such evidence. In combining this with threatening messages, De Meulenaer, De Pelsmacker and Dens (2017) proved that adherence can be improved among people from high power distance cultures. Mulder (1977) found that due to the advantages associated with occupying the higher levels of the hierarchy, it is common for people in such positions to strive to maintain the power distance that exists between themselves and those with less power.

In discussing communication from the cultural aspect, Hall (1976) divided the context into two: Eastern countries (including Malaysia), which have a high-context culture, and Western countries, which generally have a low-context culture. As a society with a high-context culture, the Malaysian *"... communication or message is one in which most of the information is either in the physical context or internalized in person, while very little is in the coded, explicit, transmitted part of the message"* (Hall, 1976: p. 91). To further clarify, non-verbal communication and sociocultural values in high-context cultures carry higher-value messages in comparison to messages that are communicated either verbally or in writing. As such, verbal or written communication in a high-context culture does not require too much detail or

contain explicit information in the message as the remainder is conveyed via mutual understanding and trust (Hallenbeck, 2006; Hooker, 2012). Besides, since non-verbal communication, including facial expressions, eye contact, body gestures and tone of voice, carries greater meaning than verbal communication, it is common in a high-context culture for the words uttered to not convey the actual meaning of the message (Hooker, 2012). Thus, communication in a high-context culture tends to be more indirect or ambiguous compared to communication in a low-context culture where speech is more direct and precise (Hooker, 2012). Hooker (2012) further explained that in this type of culture 'yes' may not necessarily indicate agreement as it can also be used to signal understanding or acknowledgement. Similarly, when an individual in a high-context culture does not agree with something they will tend to use 'maybe' or 'I will think about it' as opposed to stating 'no'.

Communication in a high-context culture also does not depend simply on verbal and non-verbal speech but is heavily dependent on the other cultural dimensions mentioned in this section. Due to the fact that societies with a high-context culture are also collectivist, with a high value placed on relationships with others, individuals generally use indirect speech or non-verbal cues in order to save face or avoid causing offence to their counterparts (Hooker, 2012). This contrasts with individualist Westerners, who tend to be franker and express themselves more openly, as their main concern is the upholding of justice and their own rights. Thus, decision-making in such low-context societies tends to be carried out more immediately, during the meeting or encounter, whereas in a high-context culture, deliberation and decisions generally take place behind the scenes (Hooker, 2012).

Hooker (2012) also mentions that it is becoming more common nowadays for low-context communication to be found in a high-context culture as a result of Western influences and technological advancement. This is in parallel to the assertion by Helman (2007: p. 3) in his book *Culture, Health and Illness*, where he described culture as *"... an increasingly fluid concept, which in most societies is undergoing a constant process of change and adaptation"*. Globalisation and Malaysia's

modernisation and rapid economic development have led to social change and mobility (Mohd Darbi, 2006; Noordin & Jusoff, 2010). Therefore, individualism is further permeating Malaysian society and, as asserted by Mohd Darbi (2006), is becoming common within affluent societies that are financially, emotionally and socially independent. Data from a study by Noordin and Jusoff (2010) also indicate a slight shift in the Malaysian collectivist society, reflecting the fact that members of the society are becoming more competitive in spite of the enduring value they place on social relations, family integrity and the concept of self-sacrifice. A similar change was also detected by Ken and Ying (2013), who found a lower value for the power distance index compared to that found in Hofstede's study in 1980.

Similarly, the culture of uncertainty avoidance among Malaysians is changing. Hofstede (1980) employed an uncertainty avoidance index to measure the ambiguity tolerance level when describing different cultures in different countries. Malaysia was found to be among the lowest in this dimension, together with Great Britain and Ireland (Hofstede, 1980). This indicates that Malaysians have a more relaxed attitude to dealing with uncertainty compared to countries that scored higher, including Greece and Portugal. However, a more recent study by Ken and Ying (2013) indicated that uncertainties are no longer well accepted among Malaysians, who are becoming more concerned with regard to their future. As such, more in the way of written rules and guidelines are required to reduce this uncertainty (Hofstede, 1984). Ken and Ying (2013) further suggested that this change is due to several factors, including political uncertainty, high economic growth and increased levels of competitiveness, which can also be cited as the underlying factors of the transformation of the other Malaysian cultural dimensions mentioned above.

Overall, discussion of the Malaysian cultural background indicates how Malaysians live in significantly different social and cultural contexts from those found in Western countries. However, more recent studies have served to demonstrate its transformation. Consequently, there is a greater possibility that the values and demands of the society are also evolving. This further complicates the Malaysian

cultural condition, and caution is recommended when attempting to understand Malaysian behaviours and practices.

1.5.2 Document review and analysis in Malaysia regarding patient involvement in decision-making

A review of government documents on patient involvement in decision-making was conducted in order to obtain a better overview of its implementation in Malaysia. A search of the internet resulted in a few of MOH Malaysia official documents mentioning this notion.

The Malaysian Medical Council, as the governmental body that regulates medical practitioners and physicians in Malaysia, makes no specific mention in their Code of Professional Conduct for Medical Practitioners of any requirement for patient involvement in deliberation about their treatment decisions (Malaysian Medical Council, 1986). Nonetheless, it is something that is highlighted in their supplementary document of Good Medical Practice, which delineates the duties of physicians in Malaysia (Malaysian Medical Council, 2001). Physicians are required to establish a good and reciprocal relationship with their patients as an aspect of ensuring patients' well-being. Several of the points made in relation to facilitating physicians to achieve the recommended partnership and collaborative relationship were found to be in accordance with elements of shared decision-making. These include the following: *"frank discussion in which the patient's needs and preferences and the doctors' clinical expertise are shared to select the best treatment option"* (p. 8), and *"give the relevant options when discussing treatment, and the limitation and possible complications"* (p. 9).

For nurses in Malaysia, patient involvement in decision-making is mentioned by the Nursing Board Malaysia, as the regulatory body of nursing practice in Malaysia, in their Code of Professional Conduct for Nurses (Nursing Board Malaysia, 1998). Their guidelines encourage nurses to work *"… cooperatively with the patient and his family and respect their decisions about his care"* (p. 1). Emphasis is also placed in

this document on the need for nurses to *"... give correct information and education to each patient according to the needs"* (p. 2), and to *"maintain informed consent in the provision of nursing care to all patients"* (p. 1). Nurses' responsibility as the advocators of patient involvement in decision-making is further described as they are responsible *"to promote and protect the interest of the patient when he is incapable of communicating his needs and protecting himself"* (p. 2). Similar recommendations are made by the Pharmacy Board Malaysia, as the Malaysian governmental body that controls pharmaceutical activities, in their Code of Conduct for Pharmacists and Bodies Corporate (2009), in which descriptions pertaining to pharmacists' professional relationship with patients are outlined (Pharmacy Board Malaysia, 2009). Pharmacists should *"... determine the patient needs, values and desired outcome"* (p. 5) in order *"... to involve their patients or clients in the decisions regarding their health"* (p. 5). However, no description was found with respect to allied HCPs in Malaysia.

Some descriptions related to patient involvement in decision-making were also found in the current Malaysian T2DM Clinical Practice Guidelines (CPG) (MEMS, 2016) and Diabetes Education Manual 2016 (Malaysian Diabetes Educators Society, 2016). These are produced to promote standardised guidance and are for use by HCPs dealing with patients with diabetes in Malaysia. In the CPG, the recommendation is for patients' educational strategies, including dietary counselling, to be individualised based on their personal characteristics, including their health, beliefs, information needs, personalised goals, cultural preferences and individual lifestyle. Consistent with this, an analogous emphasis is apparent in the Diabetes Education Manual 2016 as it also recognises a change of approach in encouraging the self-management of T2DM, with a shift from an instructional style to patient empowerment and improved self-efficacy. However, it also focuses only on the involvement of diabetes patients in decisions relating to non-pharmacological modalities, including diet therapy and physical activity. In both documents, there was a lack of description pertaining to the individualised pharmacological modalities that consider patients' preferences, needs, values and beliefs.

The other Malaysian document mentioned patient involvement in decision-making is the Malaysian Medical Council Guideline: Consent for Treatment of Patients by Registered Medical Practitioners (Malaysian Medical Council, 2016). This document by the Malaysian Medical Council is aimed at guiding physicians regarding the concept of consent to care. Within this guideline, consent is defined as *"... the voluntary acquiescence by a person to the proposal of another; the act or result of reaching an accord; a concurrence of minds; actual willingness that an act or an infringement of an interest shall occur"* (p. 1). Similar to most parts of the world, there is a legal requirement for consent to be obtained from the patient, his or her family or legal guardian in respect of every examination, procedure and treatment, following HCPs' sharing of related information. Nonetheless, unlike in shared decision-making, patient involvement in informed consent is restricted only to whether they agree or disagree with the recommended examination or modalities, with no mention of patients' contribution to the selection of the recommended option in the first place.

1.6 Chapter summary

The global and Malaysian trends of T2DM are alarming. These include its prevalence, patients' adherence to their T2DM management and also the high incidence of T2DM-related complications. As such, shared decision-making, as a model of involving the patient in decisions, has been introduced and encouraged as part of a continuous and persistent effort to improve the service provided to patients. This is being carried out with the ultimate goal of improving the health outcomes of patients. Nonetheless, despite the shared decision-making approach having been in place for more than 20 years the review of the Malaysian government documentation on patient involvement in decision-making and shared decision-making uncovered only superficial explanation of these matters, despite them being recognised as important and having a distinct contextual background. Thus, a comprehensive literature review was performed to further explore this area, the results of which are presented in the following Chapter 2.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter is divided into three main parts. Part 1 provides an overview of patient-centred care, which is the foundation of shared decision-making. The first part of this chapter also discusses the theoretical perspective of patient involvement in making health decisions, including the shared decision-making model. Part 2 begins with the search strategy used for the existing literature on patient involvement in decision-making and shared decision-making. The second part also presents the findings from the review, covering the preferences of patients and HCPs and the factors related to patient involvement, its implementation and outcomes. Part 3 contains an overview of Malaysia, which is the setting for this study, along with descriptions of its healthcare system, including its T2DM management. This section also includes an analysis of empirical studies around the studied area in the Malaysian context. Finally, the chapter summarises how this study fills the gaps in the current knowledge in the area before presenting the statement of problems of this study together with my personal reflections.

2.2 Part 1: Patient-centred care and healthcare decision-making

A healthcare system is an environment in which providers are bound to a certain level of professionalism. Eliot Freidson (1971), in his book *Profession of Medicine*, highlighted the authority held by HCPs stemming from their altruism (they work in the best interests of their patients), expertise (they possess technical knowledge not readily accessible to others) and self-regulation (they superintend their own profession without interference from others). Due to these factors, patients' medical and health management has traditionally been planned and determined by HCPs with little or no consideration given to the preferences, values and needs of patients. However, the transformation of the contemporary healthcare landscape following the rise in patient autonomy and the consumerism that has triggered patient activation and empowerment has increased the demands on this paternalistic practice, which is based on the traditional biomedical model to change. This need for change has been

illuminated by the upsurge in the concept of patient-centred care within the healthcare system.

2.2.1 Patient-centred care

Patient-centred care is a concept that has been interchangeably termed 'person-centred', 'people-centred', 'client-centred', 'resident-centred' and 'relationship-centred' (Nolan, Davies, & Brown, 2006; McCormack, Karlsson, Dewing, & Lerdal, 2010; Morgan & Yoder, 2012). In this thesis, the term patient-centred care is used when referring to the concept, unless one of the other terms is more suited to the context being discussed or if the existing frameworks being mentioned use these other terms.

Patient-centred care has been defined differently from various perspectives and in different contexts (Morgan & Yoder, 2012; Lusk & Fater, 2013). Generally, the Picker Institute and the Institute of Medicine (IOM) are among the renowned bodies in the healthcare system to have pioneered this concept in a bid to shift the focus of the healthcare service onto the individual instead of focusing solely on disease. IOM (2001) described patient-centred care as care that is respectful and responsive to patients' individual needs, preferences and values, with this definition proceeding to inform all clinical guidelines. As mentioned in Chapter 1, Malaysia is witnessing an increasing demand for healthcare services, yet it has limited resources with which to provide them. By placing the patient at the centre of their care, it is anticipated that the healthcare service can be improved as the patient obtains the care they need, when they need it, at the same time as being encouraged to participate more in their health management (Coulter & Collins, 2011). Consequently, patient-centred care may facilitate the improvement of patients' health at the same time as reducing the burden and cost of healthcare services (de Silva, 2012).

The involvement of patients in their own care plans and disease management is a key element within the concept of patient-centred care. It has become established as a priority in the healthcare system over the past few decades due mainly to it having been proven to improve patient outcomes as a result of them being more actively

engaged (Michie, Miles, & Weinman, 2003; Longtin et al., 2010). Nonetheless, patient involvement in healthcare is a complex and multi-layered concept as it also covers other terms such as 'partnership' (Sahlsten et al., 2008), 'concordance' and 'patient empowerment' (Mead & Bower, 2000). Furthermore, the concept of patient involvement in decision-making refers to a form of practice in which patients and HCPs address the importance of a good mutual affiliation within which relevant but sufficient information is exchanged in an effort to encourage patients to become actively involved in the decision-making process (Sahlsten et al., 2008; Thorarinsdottir & Kristjansson, 2014).

The Picker Institute identifies the following eight characteristics of patient-centred care: (1) respect for patients' values, preferences and expressed needs; (2) the coordination and integration of care; (3) information, communication and education; (4) physical comfort; (5) emotional support and alleviation of fear and anxiety; (6) involvement of family and friends; (7) transition and continuity; and (8) access to care (Gerteis, Edgman-Levitan, & Delbanco, 1993). The same eight characteristics have also been recommended by the IOM in explaining this concept so that the needs of each patient can be met (IOM, 2001).

Mead and Bower (2000) also put forward a number of propositions with regard to the concept that they developed based on a review of the conceptual and empirical literature. Theirs is one of the most prominent works on patient-centred care, with their propositions including (1) the biopsychosocial perspective; (2) the *'patient-as-person'*; (3) sharing power and responsibility; (4) the therapeutic alliance, and (5) the *'doctor-as-person'*. Yet it has been argued that Mead and Bower's (2000) propositions regarding the patient-centred approach are not applicable to non-physician HCPs as nursing literature was excluded from their concept of patient-centred care. Additionally, Gillespie, Florin and Gillam (2004) outlined that different HCPs have a different focus when describing this concept based on their own professional roles and interests. However, Kitson, Marshall, Bassett, and Zeitz (2013), in a further narrative review and synthesis of the existing literature on

patient-centred care in different medical and healthcare practices, found an overlapping of the described elements.

In this section, the discussion on patient-centred care is based on the description of the person-centred framework developed by McCormack and McCance (2017) which focuses on this concept in a broader context and covers a wider range of healthcare viewpoints. In 2006, McCormack and McCance took their first framework, which focused only on the concept in nursing practice, and developed it into this current concept that covers not only nursing but also overall healthcare practice, thus reflecting the contemporary inclusiveness of healthcare philosophy (McCormack & McCance, 2017). In combining the existing conceptual frameworks on patient-centred care with their empirical work, the conceptual framework was developed and updated accordingly. Their framework comprises four constructs, as follows: 1. prerequisites (HCPs' attributes); 2. the care environment; 3. person-centred processes; and 4. expected outcomes.

McCormack and McCance (2017) acknowledge both the imperative role played by HCPs and their strong influence in shaping the level of patient involvement in their own management. This is because, as previously mentioned, even though healthcare systems around the globe are continuously changing, HCPs remain to be the gatekeepers to these systems and continue to play a major role in delivering care to patients. McCormack and McCance stipulate this as a prerequisite in their person-centred care framework, and it is the first construct within it. The construct outlines the attributes of HCPs that are considered important, including HCPs' professional competence, their interpersonal skills and commitment, personal characteristics, including their beliefs and values, and their sense of knowing.

The framework's second construct describes the environment in which care is provided. In this construct, emphasis is given to the importance of an environment that is both conducive to and supportive of person-centred care, including the sharing of power and responsibility and the therapeutic alliance that exists not only between

patients and HCPs but also between different groups of HCPs. This is combined with other characteristics that include an appropriate mix of skills (including the communication skills of patients and HCPs), supportive organisational systems that facilitate shared decision-making and the physical environment. It is also important that there is the latitude for innovation and risk-taking. In having these characteristics, it can be said that McCormack and McCance's framework addresses the involvement of other HCPs and the importance of the environment in managing a patient's health condition, which is something that is lacking in the patient-centred medical framework by Mead and Bower (2000).

In facilitating the involvement of patients in their management, including in decisions, McCormack and McCance (2017) suggested different healthcare activities to enable HCPs to assess and take into consideration each patient's beliefs and values when formulating an individualised care plan for them. Patients' personal interpretation, meaning, socio-economic and cultural background, and motivation and experience of illness should all be considered. The aim is to provide a holistic and effective form of management to each individual patient. Besides, it is also important that HCPs are sympathetic towards their patients so that they can engage with them and work together in making decisions at the same time as providing a holistic level of care (McCormack & McCance, 2017). Also in this construct, McCormack and McCance (2017) place further emphasis on shared decision-making by identifying the approach as one of the methods for delivering person-centred care.

The framework by McCormack and McCance (2017) went further and described the outcomes of the person-centred care concept. In this construct, they emphasised the importance of including measurable outcomes to serve as reliable indicators of the effectiveness of the concept. These outcomes include patients' satisfaction, a good experience and involvement in their care, patients' feeling of well-being and the creation of a healthy culture or therapeutic environment. They recommend a number of methods by which to measure the outcomes, including a person-centred practice inventory, observations of practice, narrative and story, and routine data. The

recognition of these measurable outcomes may also be one of the reasons for the adoption of the concept of patient-centred care by the global healthcare system (Kitson et al., 2013). Consequently, the adoption of patient-centred care in the healthcare system adds another dimension due to the fact that the target of the service provided no longer revolves solely around clinical outcomes.

The following Figure 1 is a visual representation of the latest person-centred practice framework. This framework includes McCormack and McCance's latest addition to the concept in the form of the macro context of healthcare. In this construct, they emphasise the importance of both health and social policy, the strategic framework, workforce development and strategic leadership. This supports the integration of patient-centred practice in a broader sense within the healthcare system.

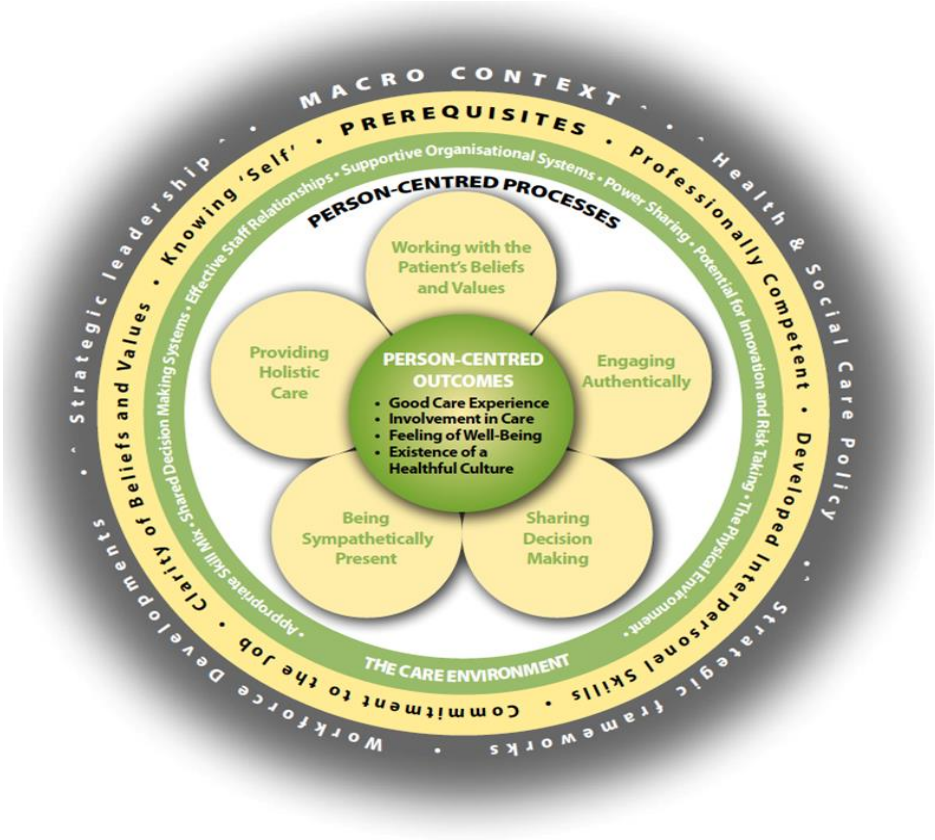

Figure 1: The Person-centred Practice Framework by McCormack and McCance (2017)

Nonetheless, as attractive as patient-centred care may appear, Fredericks and colleagues (2012) highlight some of the challenges that may be faced in terms of integrating patient-centred care into the healthcare system, including the initial cost of training HCPs, the inherent medical power and knowledge, and a lack of resources. These challenges sit alongside evidence that the outcomes of any patient-centred care initiatives may not be sustained over time and that some patients feel more comfortable leaving the responsibility for managing their health condition to their HCPs, which has notably been observed among the elderly and less educated groups (Levinson, Kao, Kuby, & Thisted, 2005; McMillan et al., 2013). Furthermore, the discussion around this concept by Dubbin, Chang and Shim (2013) also highlights the lack of consensus with regard to how the concept is conceptualised, institutionalised and implemented across practices, different groups of HCPs and patients.

However, due to its relevance and benefits, the adoption of patient-centred care across a wide range of T2DM management measures has been endorsed by bodies around the world, including by the ADA (2015), NICE (2015) and MEMS (2016). Besides, among the research on the management of illness, patient education and participation, Longtin and colleagues (2010) suggest that patient involvement in decision-making is considered to be the most fundamental right of the patient in the field of biomedical ethics

2.2.1.1 Patient involvement in decision-making

The continuum of patient involvement in decision-making ranges from paternalistic models, through advocate models or informed non-dissent, shared decision-making or equal partners, to models of informed choice or clinicians' recommendations for increased patient control and, ultimately, patient-driven decision-making (Gafni, Charles & Whelan, 1998; Kon, 2010). As mentioned earlier, the patient–HCP relationship has evolved from being paternalistic to patient-centred in nature. Hence, it is important for HCPs to identify, facilitate and support patients' preferences with regard to their participation in decision-making. However, a thorough analysis of this

matter is suggested due to the potential for misinterpretation of patients' ability to be involved in the decision-making process and their ability to perform self-management (Florin et al., 2006).

Similar to patients' involvement in managing their health, various different terms have been used by different parties to describe patients' involvement in making decisions concerning their management, with these including 'shared decision-making', 'participatory decision-making', 'informed decision-making', 'evidence-informed patient choice' and 'informed choice' (Parchman et al., 2010; McCaffery, Smith & Wolf, 2015). Each term is defined differently, but the important point is that each conveys a sharing of information and involvement in the decision-making process on the part of patients and HCPs.

2.2.2 Models of decision-making

Owing to its importance, decision-making in health and medicine has been discussed and studied from many different angles. Consequently, large numbers of models and theories have been developed and have emerged in different fields to explain decision-making in relation to those fields, including in medicine and health, psychology and economics. These include expected utility theories, information processing theories, social judgement theory, the theory of reasoned action (Fishbein & Ajzen, 1975; Ajzen & Fishbein, 1980), and normative, prescriptive and descriptive models (Bell, Raiffa, & Tversky, 1995). However, for this study, the focus is on patient involvement in decision-making, with the discussion around this based more on models that explain not only patients' sociocultural factors and their access to resources but also on the patient–HCP relationship. As such, patient–HCP decision-making models are used as the main models in this study. These models include paternalism, shared decision-making, interpretative decision-making and informed decision-making, as illustrated in the following *Figure 2*, which is modified from Wirtz, Cribb, and Barber (2006). The explanation of shared decision-making and interpretive decision-making is presented last despite these appearing in the middle of the continuum since explanations of paternalism and informed decision-making are essential to an understanding of the former two types of decision-making.

Additionally, some of the other aforementioned models and theories are used when discussing the findings in this study.

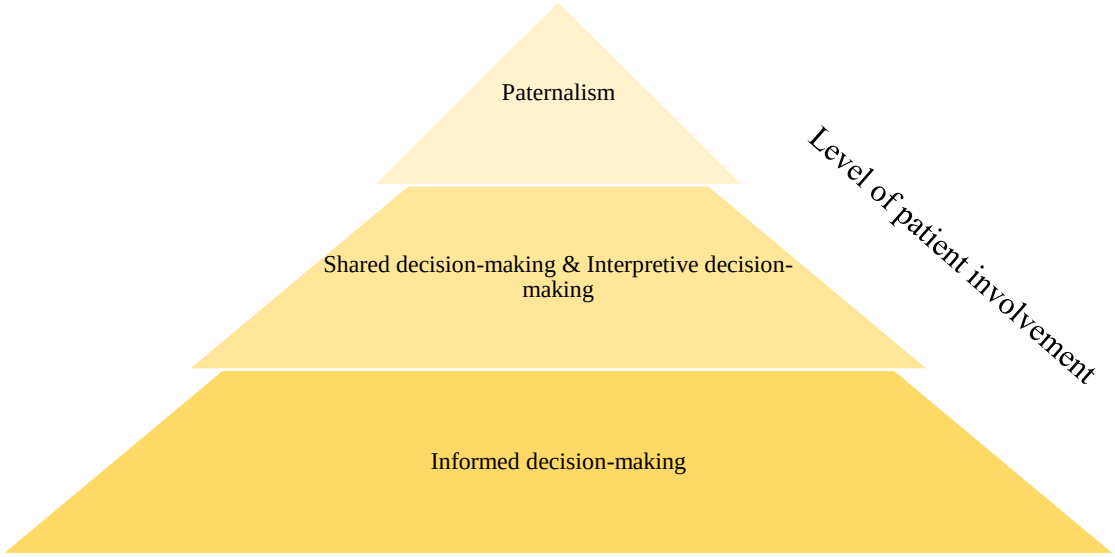

Figure 2: Decision-making models (modified from Wirtz, Cribb and Barber, 2006)

2.2.2.1 Paternalistic decision-making

The paternalistic model was widely adopted by healthcare systems in the past due to its alignment with the central element of the Hippocratic oath and the traditional concept of the professionalism of HCPs, especially that of physicians. An earlier definition of paternalism in the *Oxford English Dictionary* (1989) was *"... the principle and practice of paternal administration; government as by a father; the claim or attempt to supply the needs or to regulate the life of a nation or community in the same way as a father does those of his children"*. From this standpoint, HCPs were considered to be the best decision makers to act on the patients' behalf as they had the requisite knowledge and understanding of the patients' medical needs and interests. However, in the current edition of the dictionary, this positive-sounding definition has shifted to one with a more negative tone, as *"... the policy or practice of restricting the freedoms and responsibilities of subordinates or dependants in*

what is considered or claimed to be their best interests" (Oxford English Dictionary, 2005). This aligns with the shift in the medical and health landscape that is currently more supportive of patient autonomy and involvement in decision-making (Hafemeister & Gulbrandsen, 2009). Nonetheless, Beauchamp and Childress (2013: p. 215), in their book *Principle of Biomedical Ethics*, further define paternalism in a more neutral tone as *"... the intentional overriding of one person's preferences or actions by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preference or actions are overridden"*. This describes how, in this model, HCPs uphold the values of beneficence and nonmaleficence, along with the justification that patients' autonomy may potentially bring harm and would not benefit them in terms of some of the decisions that need to be made (Hafemeister & Gulbrandsen, 2009; Pelto-Piri, Engström, & Engström, 2013). Sjöstrand, Eriksson, Juth, and Helgesson (2013) further argue that paternalism and autonomy are not necessarily entirely antithetical, as, in some conditions, patients' decisions can be overruled as part of an HCP's effort to protect the autonomy of patients.

Nonetheless, in this model, patient involvement in decision-making is generally denied as decisions are made solely based on HCPs' expertise in determining the best course of treatment and management for restoring their patients' health (Emanuel & Emanuel, 1992). This is because patients are assumed to have limited to no medical and health knowledge, thus rendering them unqualified to determine what is best for them from a medical perspective. Consequently, the role of the patient in this model is to tacitly agree and comply with their HCPs' orders (Laine & Davidoff, 1996; Sagoff, 2013). Sagoff (2013) further argues that a patient's preferences will not matter if a patient trusts that their HCPs are doing what is best for them; that is, they are acting in the patient's best interests. Furthermore, Emanuel and Emanuel (1992) argue that paternalism is supported by the more recently introduced informed consent despite the fact that it is aligned with the Bolam principle, which was established in an effort to prevent medical negligence. This is because it is common for the information provided as part of the consent-obtaining process to be shaped by HCPs in order that patients will accept and agree with the HCPs' decisions (Emanuel & Emanuel, 1992). For the same reason, informed consent is described as a product

of soft paternalism by Cohen (2013) and is also referred to as paternalism justified by consent by Beauchamp and Childress (2013). Wirtz and colleagues (2006), on the other hand, argue that in doing this, the patient does actually become involved in the decision-making.

Nevertheless, this one-directional model can be considered as a therapeutically superficial model in terms of decision-making, especially when it comes to chronic medical problems. This is because a decision is made based only on an objective judgement by the HCPs based on a patient's medical complaints, the HCP's assessment of the patient's medical needs and the patient's biomedical test results. This runs contrary to the Chronic Care Model (Bodenheimer et al., 2002) in which the management of patients with chronic medical conditions requires them to be fully informed and actively involved in their overall health management (Coleman et al., 2009). Thus, patients' subjectivity and experiential knowledge are also fundamental in deciding what is best for them.

2.2.2.2 Informed decision-making

The informed decision-making model is also known as the informative model (Emanuel & Emanuel, 1992). In this model, patients have full accountability for the deliberation and decision based on all of the relevant information that is provided by their HCP (Emanuel & Emanuel, 1992). When compared to shared decision-making, the HCPs' personal values and understanding of the patients' values are less important since their role is to act only as information providers and executors of the treatments or interventions selected by the patients. Nonetheless, it is fundamental that the information provided is sufficiently comprehensive to enable the patients to make a decision that aligns with their values (Emanuel & Emanuel, 1992).

2.2.2.3 Shared decision-making and interpretive decision-making

Sitting in the middle of the continuum of decision-making models are interpretive decision-making and shared decision-making (Wirtz et al., 2006). Emanuel and

Emanuel (1992: p. 2221) outline that the main aim of interpretive decision-making *"… is to elucidate the patient's values and what he or she actually wants, and to help the patient select the available medical interventions that realize these values"*. In terms of the final decision, similar to the informed decision-making model, it is the patient who will decide.

The shared decision-making model, on the other hand, is considered to contain an optimal and ideal balance of patient and HCP interaction (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982). This is because, according to Sandman and Munthe (2010), the shared decision-making model differs from the interpretive model in that the latter is a model in which HCPs help patients to interpret and understand their preferences and values in relation to the situations and it is then up to the patients to make a decision based on this. The former, in addition to considering patients' personal values and preferences, takes into account the HCPs' technical expertise and, on some occasions, compromise and negotiation are needed between the two parties. This serves to make collaborative, shared decision-making more relevant to the management of chronic diseases, including diabetes. Decisions under the shared decision-making model are made based on both the HCPs' medical and health knowledge and the patients' personal values and preferences, in order to achieve the most effective therapeutic management for improving patients' behaviours and outcomes (Montori et al., 2006; Drewelow et al., 2012).

Patient involvement in decision-making has been researched and written about internationally for more than three decades. One of the earliest mentions of the approach was by the President's Commissioner for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research in 1982, in promoting the balance between patients' autonomy and HCPs' ethical sense of beneficence and nonmaleficence. It is an approach in which HCPs and patients collaboratively select tests, treatments, management or support packages (Coulter & Collins, 2011). Due to the fact that the current medical and health environment limits the ability of HCPs to function as patient advocates and have total control of the required resources,

patients' trust in their HCPs may be reduced (Mechanic, 1998), with paternalism no longer accepted unquestioningly by patients (Chin, 2002). This phenomenon is currently spreading due mainly to patients' growing access to medical-related information (Diaz et al., 2002) and increased societal demands for HCPs to adopt a more encouraging attitude when providing care for their patients, in contrast to them delivering only their medical knowledge and skills (Gelhaus, 2013). This points to the need for a better way for patients to have control over their care. Thus, as a concept that encourages patient involvement in the decision-making process, shared decision-making fulfils this particular purpose (Weston, 2001).

However, as mentioned earlier in the introduction chapter and paternalistic decision-making section, this is not the only reason why the shared decision-making model is important in determining patients' management of their care. Patients with a chronic condition have to perform the self-management regimen within their own homes, thus elevating the value of patient autonomy in the management of chronic illnesses, including T2DM. Furthermore, previous studies have proved that a lack of adherence to a treatment regimen is often associated with autonomy as it serves as a means by which patients are able to express their preferences, especially if they consider the regimen in question to be insufficiently flexible, too limiting or that the choice of treatment was made by the physician (Peek et al., 2008; Sandman, Granger, Ekman & Munthe, 2012).

Additionally, a growing body of literature has highlighted that patients with unbiased information about their treatment options end up receiving less invasive and lower-cost services which are better aligned with their preferences, beliefs and values compared to patients who have not had access to the same kind of information, thereby leading to more cost-effective care (Veroff et al., 2013; Stacey et al., 2014). This is because patients tend to make more conservative judgements which have the effect of reducing unwarranted management variation and cost (Stacey et al., 2014). Studies have also revealed that both patients and HCPs described shared decision-making as the paramount approach when it comes to patient and public involvement in healthcare, which will therefore increase patient knowledge, in addition to their

confidence in decisions, satisfaction and adherence (Peek et al., 2008; Rise et al., 2013; Stacey et al., 2014). These become the reasons why many countries around the world, including the UK, USA, Canada and Germany, are endorsing or at least encouraging the integration of shared decision-making in their healthcare systems (General Medical Council, 2008; Härter, Van Der Weijden & Elwyn, 2011).

Models and definition of shared decision-making

One of the first theoretical models of shared decision-making was introduced 20 years ago by Charles and colleagues (1997) as a way of embracing patient-centred care in the healthcare system, and it has since become one of the most cited models (Makoul & Clayman, 2006). In this model, Charles and her colleagues stated that in order for shared decision-making to occur, the decision-making process must include each of the following four important elements: 1) the involvement of both parties (HCP and patient) in all phases of the process; 2) the sharing of information possessed by both parties regarding all of the treatment choices; 3) the articulation and sharing of each preferred treatment choice; and 4) the reaching of an agreement on the type of treatment to implement.

Despite this model being the most acceptable basis for shared decision-making, several basic problems and questions have nevertheless arisen. The initial development of the model was very much based on decisions related to acute or life-threatening medical conditions (Charles et al., 1997). Over the years, other researchers have worked to continuously improve and broaden the model in order for it to be applied to other medical conditions, including chronic diseases (Towle & Godolphin, 1999; Montori et al., 2006; Murray, Charles & Gafni, 2006; Elwyn et al., 2012; Entwistle, Cribb & Watt. 2012). Currently, shared decision-making has been recommended to encourage the participation of patients in self-management or psychological interventions, and to initiate long-term medications and lifestyle modification in the case of chronic diseases (Montori et al., 2006; Coulter & Collins, 2011).

The concept of shared decision-making is also defined differently and inconsistently within the literature, thus leading to a degree of perplexity with regard to the implementation and measurement of the concept (Clayman & Makoul, 2009). A systematic review was conducted to determine the range of conceptual definitions and the most frequently invoked elements of shared decision-making (Makoul & Clayman, 2006), with the finding that the definitions varied across the literature. This is aligned with a paper by Charles and colleagues (2006) in which the authors recommended a preliminary exploration of the meaning, preferences and applicability of shared decision-making across different groups of people due to the potential for cultural variations between them. As such, it is not impossible for policymakers and HCPs to make trade-offs between the elements of different shared decision-making models based on their respective ethical advantages and disadvantages (Cribb & Entwistle, 2011). Furthermore, a review by Makoul and Clayman (2006) identified that only elements of patient values or preferences and the present options were included in more than half of the conceptual definitions. This paper also listed the essential elements, ideal elements and general qualities of the shared decision-making model based on the existing models. These elements are given in Table 1 and have been used as the main tool in conducting this study in conjunction with the original model by Charles and colleagues (1997) and other existing models.

Table 1: The essential, ideal elements and general qualities of shared decision-making as emphasised in prominently cited models (modified from Makoul and Clayman, 2006)

Essential elements	Ideal elements	General qualities
Define/explain problem	Unbiased information	Deliberation
Present options	Define roles (desire for involvement)	Flexibility/individualised approach
Discuss pros/cons (benefits/risks/costs)	Present evidence	Information exchange
Patient values/preferences	Mutual agreement	Involves at least two people
Discuss patient ability/self-efficacy		Middle ground
Doctor knowledge /recommendation		Mutual respect
Check/clarify understanding		Partnership
		Patient education
		Patient participation

Essential elements	Ideal elements	General qualities
Make or explicitly defer decision		Process/stages
Arrange follow-up		

The review by Makoul and Clayman (2006) suggests that shared decision-making begins with a definition and/or an explanation of the problem to be addressed. This is followed by a presentation of the options, which may be provided not only by the HCPs but also by the patients. According to Charles and colleagues (1997), and supported by Branda and colleagues (2013), shared decision-making is most useful when there is more than one sensible choice of treatment. However, a review by Stacey and colleagues (2014: p. 3) found that shared decision-making is also useful in various situations, including *"... when there is more than one reasonable option, when no option has a clear advantage in term of health outcomes, and when each option has benefits and harms"*. In addition, not choosing any treatment options and maintaining the status quo are also considered to be options available to patients, for whatever reason they may have for this to be their preferred course of action (Elwyn, Edwards, Kinnersley, & Grol, 2000; Towle, Godolphin, Grams, & Lamarre, 2006). The review also found that the existing models emphasise how the benefits and downsides of each presented option should be equally shared and discussed so that patients may have a sense of equipoise and choose their preference without bias (Makoul & Clayman, 2006). This can be achieved through HCPs' use of decision aids, decision support tools or verbal explanations (Stiggelbout et al., 2012; Stacey et al., 2014). Stiggelbout and colleagues (2012) also argue that decision aids are more useful for use independently, outside the clinical encounter. Next, patients' views, preferences, concerns, values and ability to follow or carry out the management must be explored so that they can be compared with HCPs' recommendations and further deliberated upon according to HCPs' knowledge.

After all of the options and important information have been presented and obtained from the patients, the patients' preferred role should be identified (Makoul & Clayman, 2006; Stiggelbout et al., 2012). It is important to note that not all patients are willing to be involved in their own healthcare decision-making and prefer for the

HCPs to decide on their behalf, or else they prefer to simply agree with the recommendation provided (van den Brink-Muinen et al., 2006; Lewin and Piper, 2007; S.N. Whitney et al., 2008; Shay & Lafata, 2014). This group should not be abandoned, as this course of action may merely reflect differences in their understanding and the dominant conceptualisation of a patient's involvement in decision-making (Hoffmann et al., 2014). Their involvement in shared decision-making could be encouraged through the development of custom-made interventions which are grounded to the patients' meaning and needs from this process in order to help them participate (Hibbard & Greene, 2009; Légaré & Thompson-Leduc, 2014). According to Légaré and colleagues (2011), patients' hesitance to be involved in decision-making is not merely due to a lack of desire but rather due to a lack of self-efficacy to make their own decision.

Nonetheless, in some cases, patients are left alone to make their own decision after being informed about the available choices, without any professional recommendation and support from their HCPs, especially when they want to make an autonomous decision (Laine & Davidoff, 1996). Yet even competent patients may come to feel abandoned and depressed in the absence of good support and help from their HCPs (Davies & Elwyn, 2008). Although patients may express a preference to be more involved in making health- or medical-related decisions for themselves, they also still highly value their HCPs' suggestions and recommendations regarding the best treatment option for their health condition (Mazur, Hickam, Mazur & Mazur, 2005). This is where shared decision-making displays a further strength as it serves as a platform from which to strike a balance between two of the major principles in biomedical ethics, autonomy and beneficence, thus resulting in shared responsibility between the patients and their HCPs for the decision that is made collaboratively.

Scholars have emphasised that the role of the patient–HCP partnership and deliberation, which differentiates this model from any other decision-making model, including interpretive decision-making, should be maintained throughout the process, in order to ensure the effectiveness of shared decision-making (Makoul & Clayman, 2006; Elwyn et al., 2012; Stiggelbout et al., 2012). However, when compared to

other elements such as offering options and eliciting patients' preferences and values, the description and exploration of this element of shared decision-making is found to be lacking (Charles et al., 1997; Sandman, 2009; Wirtz et al., 2006; Elwyn et al., 2012). This may be indicative of the complexity of this element and also point to the high possibility of its absence in current practice. According to O'Connor, Stacey, and Légaré (2008), together with Tinsel and colleagues (2013), this is something that could be resolved through educational opportunities or by having a decision coach.

2.2.3 Shared decision-making model in T2DM

To reiterate, shared decision-making is beneficial to T2DM patients as it can empower the patient to take better care of themselves. Supporting this, Montori and colleagues (2006) together with Entwistle and Watt (2006) also emphasise the applicability of the shared decision-making model in the management of T2DM as a chronic illness and where patients' active involvement is more likely to be required as they need to carry out the decisions on their T2DM management without the presence of their HCPs as compared to patients with an acute condition, which is the focus of the work by Charles and colleagues (1997) on this approach. They suggested a few modifications to the shared decision-making model by Charles and colleagues (1997) as one of the most popular models of this approach, including ongoing patient–HCP partnerships as another element of shared decision-making. This addition is deemed to be important due to the chronic nature of T2DM, which involves long-term and lifelong management. Due to this, there are more opportunities to make decisions and to revise them based on the effects and patients' experience of the decisions that have previously been made. For this to be successful, it is crucial that the elements of trust and respect which are commonly fostered by an ongoing partnership continue to exist (Montori et al., 2006).

Other than the suggestion for the additional element of an ongoing partnership, Montori and colleagues (2006) also highlight the difference between shared decision-making in chronic illness compared to acute conditions, whereby consideration needs to be given to the adjustment of a few existing elements. These include information exchange, deliberation on options and deciding and acting on the decision. Besides

'technical' information about the options available to patients, they emphasise that information exchange should also include both the values and preferences of both sides based on their social, cultural and personal backgrounds. On the other hand, since T2DM is a chronic health condition, patients often make their own decisions concerning any problems that arise outside consultation time. Thus, the presentation of different options by HCPs also requires them to provide information related to each option so that a discussion about the best decision can be entered into, while at the same time information can be included that may prove helpful for patients when they encounter any difficulties outside of the patient–HCP encounter.

Montori and colleagues (2006) further raise a concern regarding the lack of attention to and exploration of the deliberation and negotiation phase. Here, the pros and cons of each option for treating a chronic illness are considered. As compared to the deliberation on acute illness, where any patient–HCP disagreements will most probably lead to disruption of their partnership and to the need for the patient to be referred to other HCPs, any disagreement in the management of T2DM provides the opportunity for further information exchange and partnership. HCPs are considered to be responsible for supporting a patient if they opt for a suboptimal yet acceptable option since this can always be revisited at the next follow-up (Montori et al., 2006). Finally, Montori and colleagues (2006) highlight the importance of HCPs' responsibility in promoting self-efficacy among their T2DM patients in carrying out the management that has been decided, in addition to the early identification of any barriers to implementation and the promotion of patients' own problem-solving skills.

2.2.3.1 Implementation of shared decision-making in the management of T2DM

In recent years, due to the benefits of shared decision-making, a growing body of research has investigated its implementation in the management of T2DM. From the review of the literature, most of the studies concerned focused on the implementation of shared decision-making in the outpatient setting, which is where most of the decisions relating to the long-term care of these patients are made. Similarly, these studies were concentrated in Western countries, with the exception of one, by Y.Y. Lee & Lin (2010), that was conducted in Taiwan, and another, by Wang and

colleagues (2017), that was carried out in China. Nevertheless, reflecting the fact that the implementation of shared decision-making is contextual, recent studies on its implementation have been more focused on patients' sociodemographic and cultural backgrounds as part of an effort to develop more tailored and contextual interventions (Peek et al., 2008; Beverly, Wray, Lacoe & Gabbay, 2014; Baig et al., 2016).

Besides, almost all of the interventions focused on the importance of patients' preference and contribution to the decisions that needed to be made. These interventions were also primarily aimed at encouraging patient involvement in decision-making, whether by using decision aids and/or by eliciting verbal responses from patients during their encounters with their HCPs in identifying the most suitable management based on the patients' contribution and HCPs' medical expertise. In doing this, the programmes were focused on both patient education and skill development. For several studies, training was provided for the HCPs, not only to introduce and encourage the adoption of newly introduced interventions but also to develop their skill to include their patients in making decisions (Corser, Holmes-Rovner, Lein, & Gossain, 2007; Mathers et al., 2012; Peek et al., 2012; Branda et al., 2013; Griffith, Siminerio, Payne, & Krall, 2016; Den Ouden, Vos, & Rutten, 2017).

The shared decision-making interventions in T2DM were found to focus mainly on the management of T2DM, comprising pharmacological therapies and lifestyle modification. Beside antihyperglycemic medications (Mullan et al., 2009; Mathers et al., 2012; R.A. Bailey et al., 2016; Den Ouden et al., 2017; Wang et al., 2017), statins were also targeted as a preventive measure for diabetes complications (Weymiller et al., 2007; Nannenga et al., 2009; Mann, Ponieman, Montori, Arciniega, & McGinn, 2010; Branda et al., 2013; Perestelo-Perez et al., 2016). For lifestyle modification, the interventions were not only focused on personalised goal setting but also extended coverage and support to the decisions needing to be made by patients outside the patient–HCP encounter. In order to do this, in some interventions shared decision-making models were integrated with other concepts or models, including motivational interviewing (Long & Gambling, 2012; Elwyn et al., 2014;

Varming et al., 2015; Swoboda, Miller, & Wills, 2017) and self-management and empowerment (Corser et al., 2007; Peek et al., 2012; Karagiannis et al., 2014; E. Whitney et al., 2017). This revealed that the implementation of shared decision-making in the management of T2DM is challenging and varied due to the chronic nature of T2DM itself.

The decision aid was found to be one of the most popular tools when implementing shared decision-making, whether used by itself or in combination with other shared decision-making methods. It was used to improve patients' understanding of their illness and the shared decision-making interventions, to facilitate HCPs in conveying important information during their encounters with patients and encourage shared decision-making behaviour among HCPs (Corser et al., 2007; Mullan et al., 2009; Mathers et al., 2012; Denig, Schuling, Haaijer-Ruskamp, & Voorham, 2014; Gillani & Singh, 2014; Karagiannis et al., 2014; Buhse et al., 2015; McBride et al., 2016; Perestelo-Perez et al., 2016; R. A. Bailey et al., 2016; Den Ouden et al., 2017; Wang et al., 2017). Other methods were also employed by these existing interventional studies, varying from the conventional methods of one-to-one consultation (McBride et al., 2016; Peek et al., 2012) or peer/group support (Peek et al., 2012) to unconventional methods that used information technology (IT) software (Ma, Warren, Phillips, & Stanek, 2006; Klonoff, 2013) and electronic health record data (Wang et al., 2017). Similar to decision aids, these methods were used either on their own or were integrated with each other.

With regard to the outcomes of the programmes, discussions were held not only on their effects on patients but also on the feasibility of the programmes. Based on a systematic review by Saheb Kashaf and colleagues (2017) on the outcomes of shared decision-making programmes in the management of T2DM, which also included most of the previously mentioned interventions in this section, positive outcomes were more visible in patients' knowledge despite the question of the validity of the measuring tools. Significant improvement was also detected in patients' decision quality and risk perception. Nevertheless, the same significant improvement was not noticeable in patients' clinical outcomes, including their HbA1c level, as only a

study by Parchman et al. (2010) showed a significant improvement in this clinical outcome. Saheb Kashaf et al. (2017) argued that this may be due to measurement bias or the fact that the shared decision-making model itself may not serve the purpose of improving patients' biomedical status. Similarly, the review also identified a lack of improvement in adherence, satisfaction, trust in physicians and quality of life, despite these aspects not being used as indicators of shared decision-making interventions as compared to clinical outcomes. However, this minimal impact may be due to the fact that these programmes were short-term in nature and the outcomes were mostly measured shortly after the interventions, thereby highlighting the need for long-term shared decision-making interventions and outcome studies. This may also indicate the importance of integrating shared decision-making models with other concepts, which was lacking in the studies included in the review paper, in addition to a re-investigation of the shared decision-making concept and its implementation (Saheb Kashaf et al., 2017).

2.2.4 Section summary

Patient-centred care, including shared decision-making, has been greatly accentuated in the current healthcare system. Compared to other decision-making models, shared decision-making may serve as a better model for patients with T2DM, who are often required to actively manage their illness on their own. This is because, in this collaborative approach, patients' preferences, needs and values are greatly respected and taken into consideration in decisions while also retaining the expertise of HCPs. Nonetheless, the review of interventions based on the shared decision-making model revealed this to be a challenging task, mostly due to the chronic nature of T2DM and its complex management arising from its classification as a human biological dysfunction that is closely related to human physiology, psychology and behavioural aspects. In addition, patient self-management is considered to be the biggest component of T2DM management, and this needs to be taken into consideration when planning any interventions related to the illness. These have contributed to a complicated process of providing comprehensive care for patients, at the same time as having to consider patients' concerns and preferences. These challenges can be clearly seen in the studies on the effectiveness of the interventions that have adopted

this model. Despite including a variety of methods, very few of these interventions have been shown to effectively improve the condition of patients, particularly with regard to their clinical outcomes. Nonetheless, clinical outcomes may not be the best way to measure effectiveness owing to the fact that the shared decision-making model is a tool to help identify the best-suited decision versus the ideal decision. Thus, the minimal effects of shared decision-making programmes on clinical outcomes should not act as a barrier to its future implementation in managing T2DM, but rather they should serve as a catalyst for improving both its implementation and the model itself.

2.3 Part 2: Research into patient involvement in decision-making and shared decision-making in T2DM

2.3.1 Overview of reviewing the literature

The main aim of this review was to explore and identify the relevant literature on patient involvement in decision-making and shared decision-making in the management of T2DM patients. This section presents a critical analysis of the most prevalent areas that are discussed in the reviewed literature. These include the preferences for patient involvement in making decisions, factors related to patients' involvement, HCPs' inter-professional collaboration and the outcomes of involvement.

2.3.2 Searching and reviewing the literature

The search for journal articles was conducted on Cinahl, Cochrane, Embase, MEDLINE, PubMed and PsycINFO. The initial searches were conducted in October 2014 and were regularly updated as the thesis was developed. The search was limited to a period from 2000 to 2017 as studies from this time were most likely to reflect the current discussion around patient involvement in decision-making. Studies that had not been peer-reviewed and published in English or Malay were excluded. The keywords used included 'Type 2 diabetes', 'non-insulin dependent diabetes', 'chronic illness' linked to 'shared decision-making', 'patient involvement', 'patient participation', 'partnership', collaboration' and 'decision'. The search terms were

combined using the Boolean terms ‘AND’ and ‘OR’ to produce more specific search findings. Chronic illness was included as a keyword during the initial phase of the review so that those papers that defined T2DM as a chronic illness could also be included. As such, a huge volume of papers was returned in the first stage. The outcomes of the search are presented in the following flow diagram (Figure 3) that was adapted from the PRISMA Group and used for a systematic review and meta-analysis by Moher et al. (2009). The search terms used resulted in a handful of studies which discussed patient involvement in decisions and shared decision-making from different angles. Therefore, the final results of the review were categorised into the following two main areas: 1) Patients’ and HCPs’ views and experiences of patient involvement in T2DM decision-making (section 2.3.3), and 2) Studies on patient involvement in decision-making in the Malaysian context (section 2.4.4).

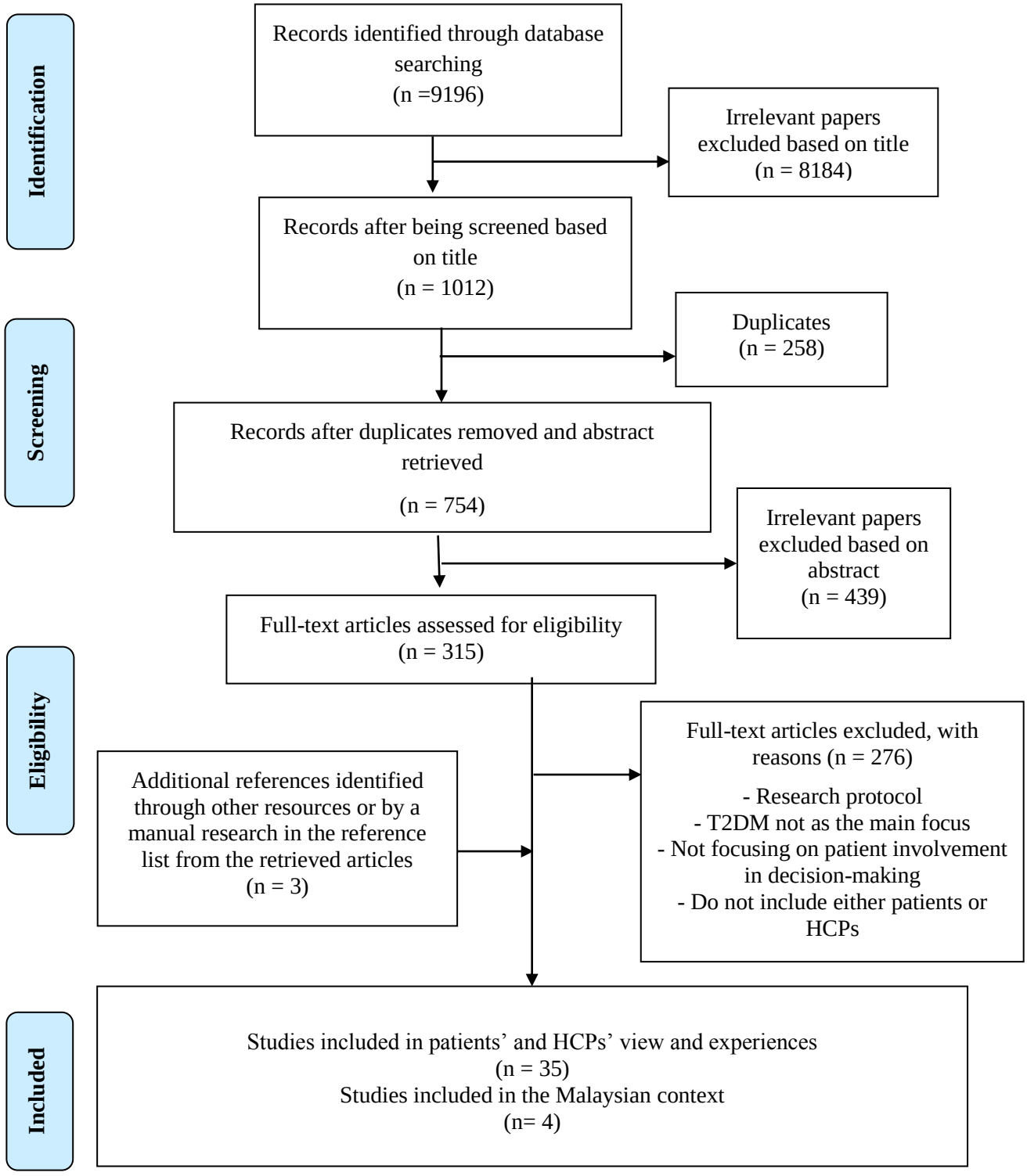

Figure 3: Literature on patient involvement in decision-making (Adapted PRISMA 2009 diagram)

2.3.3 The perspective of the patients and HCPs on patient involvement in decision-making and shared decision-making

The analysis of the literature on the views and experiences of patients and HCPs with regard to patient involvement in decision-making is presented in this section in a narrative form. A narrative overview enables the existing studies to be summarised at the same time as identifying areas that may need to be further addressed (Ferrari, 2015). As presented in Figure 3, a total of 35 articles were reviewed presenting patients' and HCPs' views and experiences concerning patient involvement in decision-making. The research activities surrounding patient involvement in T2DM decision-making were concentrated in the USA, with almost half of the reviewed studies conducted in that region, with only one study found from Asia, which was conducted among Iranian T2DM patients (Rahimian Boogar, Mohajeri-Tehrani, Besharat, & Talepasand, 2013). Two studies were also found that compared participants from different countries, including one by Hajos, Polonsky, Twisk, Marie-Paule, & Snoek (2011) involving patients and HCPs from seven European countries (France, Germany, the UK, Italy, the Netherlands, Spain and Sweden) and the USA. On the other hand, patients were found to be the main focus of most of the identified studies. In those studies that included HCPs, greater attention was paid to physicians and nurses, compared to other HCPs. Only nine studies were found that included both patients and HCPs.

The identified studies explored and investigated different aspects of patient involvement in decision-making among the participants, including their understanding and expectations, perceived preferences, actual current associated factors, and their outcomes, while some also included model or theory development and validation. The findings of such exploration resulted in a discussion of the main concerns among the key individuals involved in the management of T2DM. This will further help researchers to develop and shape interventions that are based on shared decision-making models so that they fit with the study context in terms of ensuring their effectiveness.

2.3.3.1 Patients' and HCPs' preferences in and perception of shared decision-making

Preference is one of the most popular aspects to have been examined within the reviewed studies on patient involvement in decision-making. The study of preferences was mostly conducted among patients on a quantitative basis, with a greater focus on a reporting of the percentages of participants who prefer each decision-making approach. Shared decision-making was found to be generally preferred by both patients (Corser, Lein, Holmes-Rovner, & Gossain, 2010; Hajos et al., 2011; Peek, Tang, Cargill, & Chin, 2011; Stenner et al., 2011; Beverly et al., 2014; Marahrens et al., 2017; Tinelli et al., 2017) and HCPs (Shortus, Kemp, Mckenzie, & Harris, 2011) when it comes to determining a treatment and management option for patients with diabetes. However, it has also been strongly suggested that the preferences for shared decision-making among patients and HCPs are multifaceted.

Tinelli and colleagues (2017) conducted a quantitative study among diabetes patients in Cyprus who had never experienced shared decision-making and diabetes patients in England who had experienced shared decision-making. Despite this difference, the patients in both groups were found to prefer shared decision-making as they believed it would ensure they received compassionate and personalised care from their HCPs, increased accessibility to their preferred options and result in reduced waiting time. This study provided a good indication that shared decision-making is valued by patients with experience of involvement in decision-making from different sociocultural backgrounds. The finding was consistent with that of another quantitative study, by Peek and colleagues (2011), conducted among patients in the US. They found there to be no difference among different races in terms of patients' preferences regarding the attributes of shared decision-making.

On the other hand, despite the fact that the different groups of patients valued several of the same attributes of shared decision-making (i.e. involvement in choosing their own management and treatment, shorter waiting times, the opportunity to meet the

physician and being treated compassionately), Tinelli and colleagues (2017) also highlighted various differences between the two groups. The Cypriot patients were found to be more appreciative in comparison to their English counterparts with regard to the fact that shared decision-making would provide them with the opportunity to access detailed and accurate information about their diabetes condition and the options available to them, aside from having greater access to continuous care. Although not directly comparable, it is worth noting that preferences and perceptions with regard to the shared decision-making approach were not shared among patients with a similar sociocultural background as they had different health backgrounds or experiences, as shown in the study by Searle and colleagues (2008). This UK-based qualitative study included the following two different groups of patients: patients with foot ulcerations and patients without foot ulcerations. The study indicated that those patients with foot ulcerations preferred and indeed played a more passive role in discussions with their HCPs in comparison to those patients without foot problems. Thus, both Searle et al. (2008) and Tinelli et al. (2017) emphasised that the existing shared decision-making model should be modified to ensure it is suited to both the specific context of the country in which it is being applied and the patients' personal experience. Other than variations according to the patients' sociocultural and medical backgrounds, preferences among patients were also found to vary between different age groups and levels of education (Marahrens et al., 2017).

Another quantitative study, by Cvengros, Christensen, Cunningham, Hillis, & Kaboli, (2009), investigated the association between the preference for decision-making approach and the outcome of patients' diabetes management. In this US study, which was conducted quantitatively, preference by itself was not found to be associated with any outcome, but if the patients perceived that their preference was fulfilled, especially when it came to information sharing, they were more satisfied with the decision and significant improvements in their HbA1c levels were also detected. It was common for patients' preferences with regard to the shared decision-making approach to not actually be met in practice. A study by Hajos and colleagues in 2011 found that relatively few HCPs believed that their patients needed more information

and discussion concerning their diabetes management and that they often underestimated their patients' worries regarding the severity of their diabetes condition. This was contrary to the findings that the authors gathered from the patients involved in their study. The mixed-methods study involving patients, general practitioners and diabetes specialists across seven European countries (France, Germany, the UK, the Netherlands, Spain, Sweden and Italy) and the USA demonstrated that the patients preferred to have both more and the latest information about their health problems and treatment options. They also wanted to be more involved in the discussion so that their treatment plans would suit their individual needs. Thus, Cvengros and colleagues (2009) suggested that HCPs conduct a brief assessment regarding their patients' main concern that they wanted to see addressed in each consultation in order that agreement on the aim of the discussion might be reached, with the study showing that the patients believed this could lead to more successful self-management.

The topic of preference has not only been investigated among patients. Shortus and colleagues (2011) investigated preference among HCPs. A total of 29 HCPs, including general practitioners, allied HCPs and endocrinologists, were interviewed as part of their qualitative study. It was found that preferences were complex even among HCPs as they faced a dilemma in determining the right thing to do when it came to the involvement of patients in deciding their treatment modalities, which may also have resulted from the qualitative nature of the study. It was found that, despite their common belief that patient involvement would be beneficial among patients with T2DM, which is a condition requiring self-management by patients, there were discrepancies with regard to how this could be achieved and the measures that should be taken to determine the overall effectiveness of such management. Besides those HCPs who preferred and encouraged patient involvement, there were also HCPs who treated their patients by focusing mainly on their biomedical characteristics. These HCPs preferred to take a paternalistic approach based mainly on the CPG and evidence-based practice (Shortus et al., 2011).

2.3.3.2 Factors related to patient involvement in decision-making and shared decision-making

HCPs' characteristics

As mentioned in the previous section, the preferences of HCPs concerning how decisions are made affects the actual practice (Shortus et al., 2011). Based on the review, this is not exclusive to this study, as it was found that HCPs' characteristics were one of the most common factors that facilitated or limited patient involvement in decision-making. Patients found it easier to become involved in decision-making when the HCPs treated them in an approachable, respectful and compassionate manner (Entwistle, Prior, Skea, & Francis, 2008; Courtenay et al., 2009; Corser et al., 2010; Stenner et al., 2011; Detz et al., 2014; Grohmann, Espin, & Gucciardi, 2017; Tinelli et al., 2017).

Approachability was described by diabetes patients in a study by Stenner et al. (2011) as being closely related to the ways in which their HCPs treated them during their encounter. These include the willingness of HCPs to spend more time providing detailed information to patients and on establishing a good relationship with them. The qualitative study among 41 diabetes patients in the UK being prescribed medication by their nurse prescribers further explained that the patients felt encouraged to be actively involved in making decisions as they considered their nurses to be really interested in their concern and the information that they shared. This was due to their belief that they were being listened to as the nurses addressed it accordingly.

This finding is comparable to that of a study by Courtenay and colleagues (2009) that was conducted to explore the practices of nurse prescribers in managing T2DM patients in several areas of England. Comparable to the findings by Stenner and colleagues (2011) and a few other studies (Entwistle et al., 2008; Searle et al., 2008; Beverly et al., 2014; Grohmann et al., 2017), the patients who participated in this study expressed their appreciation of their nurses' positive communication behaviours, which included active listening, the provision of detailed and

understandable explanations and asking questions of patients that encouraged them to enquire about and share their problems and concerns. These empathetic behaviours led to the patients becoming further involved in planning their T2DM management when compared to their encounters with physicians. As this study involved nurses, it also contained an exploration from their perspective and found that they believed they had to use their communication skills and the perception of being more approachable in comparison to physicians in terms of helping patients to feel more at ease in disclosing important and useful information during discussions regarding their T2DM management. This showed that HCPs' facilitative behaviours were related to their realisation of the importance of the information given by their patients. Combining this with their capacity to prescribe and their expertise, patient satisfaction levels were higher compared to the care that they received from their physicians as they believed that the care and modalities chosen were those that were best suited to their preferences and values (Courtenay et al., 2009).

Entwistle and colleagues (2008) also found HCP characteristics to be an important factor in patient involvement in decision-making. In this Scottish study, 18 patients with diabetes were qualitatively interviewed and it was found that the patients' perception of their HCPs' attitude and behaviours influenced their involvement in the decision-making process. In contrast to the aforementioned studies by Courtenay and colleagues (2009) and Stenner and colleagues (2011), Entwistle and colleagues (2008) did not focus on patient–nurse encounters but rather focused more on a general sense of the patient–HCP encounter. Besides the HCP characteristics discussed earlier, the patients in the study by Entwistle and colleagues (2008) also tended to withhold their involvement if they felt they were being judged and/or blamed for their lack of adherence or achievement in relation to the optimal or ideal biomedical outcomes. The patients also expressed an interest in being involved in discussions regarding decisions with HCPs who were honest, who would treat them as an equal partner and who would respect them as both an expert and an individual with unique experience of dealing with their own T2DM on a day-to-day basis, which has also been put forward by other studies (Corser et al., 2010; Detz et al., 2014). These studies showed that besides HCPs' medical expertise, their

communication skills and attitude were found to be important factors in terms of creating a reciprocal relationship in which patients feel comfortable and safe to be actively involved in discussing their concerns, healthcare practices and preferences.

Trust

Trust was another aspect that routinely emerged from the reviewed studies in discussions on the interaction between patients and HCPs in decision-making. However, similar to the other issues related to shared decision-making, trust is also a multifaceted matter. The placing of an excessive amount of trust, or a lack of it, was found to lead to patients being actively involved in a discussion about the decisions that needed to be made (Saba et al., 2006; Searle et al., 2008; Peek et al., 2009). The HCPs in the study by Searle and colleagues (2008) outlined some of the difficulties involved, especially in the context of dealing with patients with foot ulcers. It was reported that the HCPs' efforts to engage with these patients went unreciprocated, leading to frustration among them. This was not merely due to the patients' indifference regarding their health problems and their inability to make a decision, but was also due to the fact that the issue extended beyond the patients' encounters with their HCPs. It was also due to them placing immense trust in their HCPs, with some patients believing their HCPs to be the ones responsible for managing their foot ulcer problem, in addition to them feeling they were not sufficiently empowered to manage their foot problem themselves (Searle et al., 2008). In contrast, other studies suggested that some patients did not share their concerns as their trust in their HCPs made them feel grateful and satisfied with the service that they received and the way in which decisions were made (Saba et al., 2006; Searle et al., 2008).

Peek and colleagues (2013) also reported similar findings and emphasised the advantages and disadvantages of patients' full trust in their HCPs. This study, which was part of a larger shared decision-making intervention project, extensively explored the issue of trust in this approach. Additionally, since the study was based on the experiences of African American patients in an American healthcare setting dominated by white HCPs, elements of racial and sociocultural discordance added an

extra dimension to the issue. These elements were found to negatively impact patients' trust in their HCPs and prevented them from taking an active role in decision-making. Bauer and colleagues (2014) suggested that this would harm patients further as the practice of non-adherence would become common among these patients. Nonetheless, Peek and colleagues (2013) accentuated the potential of shared decision-making to guide HCPs to properly address their patients' concerns and provide sufficient information to improve their level of trust. By doing this, the patients in this study felt encouraged to become further involved in making decisions concerning their T2DM and felt empowered to take care of themselves (Peek et al., 2013).

Information exchange

It is typical within the existing patient-centred care guidelines and models of shared decision-making to include patient–HCP information exchange as one of the important elements. In describing the meaning and experience with regard to patient involvement in decision-making, this issue also emerges as one of the important themes in the reviewed literature. For instance, a study by Corser and colleagues (2010) reported on the difficulties experienced by patients in accessing important information that might enable them to have a better understanding of their T2DM conditions and management. In this US study involving interviews with 44 T2DM patients, concerns relating to both a lack of and the provision of ambiguous information by HCPs were raised by the patients. This was especially the case concerning their biomedical status and medications. Concern was also raised in relation to the patients' reported action of requesting more and clearer information, with the HCPs having failed to address this appropriately. It can also be seen from this study that this lack of information negatively impacted the patients' perception and most probably their self-management practice as they perceived there to be a lack of connection between their self-management and the decision made during their encounter with the HCPs (Corser et al., 2010).

The findings of Corser and colleagues (2010) were found to support the request that was raised by the patients in a study by Hajos and colleagues (2011), in which the patients wanted their HCPs to share more information, including information about the available options for their medical problem and the latest information concerning their diabetes and treatment. On the other hand, despite being an indication that the patients were ready to play an active role in discussions about their decision, it was found that the patients perceived the actual length of their medical consultation to be adequate and that no additional consultation time was needed to address their need for more information (Hajos et al., 2011). This finding is aligned with the study by Stenner and colleagues (2011) in which they asserted that consultation time is not necessarily related to the quality of information shared.

A study by Peek and colleagues (2009) further explained the nature of the information that patients wanted from their HCPs. Aside from requiring more information about the biomedical results, similar to the request of the patients in the above-mentioned study by Corser and colleagues (2010), it was also crucial that information was shared using terms that patients could understand. However, it is important for HCPs to not underestimate patients' ability to understand complex concepts related to their diabetes condition and treatment as they have also been shown to desire detailed and accurate information, not merely superficial information concerning their condition and care (Tinelli et al., 2017).

In a study by Searle and colleagues (2008), the patients involved described information sharing from their side and not merely from the perspective of their HCPs. On some occasions, these patients believed that their concerns about their health problems and the information that they shared with HCPs were not being paid sufficient attention or being adequately addressed. As such, they felt it was difficult to engage with their HCPs. The importance of information exchange from the very beginning of the patient–HCP encounter was emphasised by Zoffmann and colleagues (2008) in terms of ensuring that further communication is focused on patients' individual health problems and challenges. This finding was supported by

Searle and colleagues (2008) as patients tend to refrain from asking further questions and raising concerns or sharing information due to a perception that these types of behaviours do not form part of their expected role as a patient.

The importance of information exchange between patients and HCPs was further accentuated by Peek and colleagues (2008), whereby the patients involved perceived it to be more beneficial compared to making the final decision, regardless of any preference concerning the decision-making approach. Even those patients who preferred the HCPs to make the decision about them also stressed the need for a two-way exchange of information between themselves and their HCPs. This is because the patients had a desire to be heard by their HCP. This was found to be comparable with two other studies, Saba and colleagues (2006) and Courtenay and colleagues (2009), wherein the same emphasis was highlighted by the patients. Courtenay and colleagues (2009) further emphasised that information shared by the HCPs increased patients' understanding of their illness and care, which was found by Marahrens and colleagues (2017) to be one of the facilitators of shared decision-making.

In contrast to the findings of the previous studies, where the patients expressed their desire for more information on decision-making, Stenner and colleagues (2011) found that the patients in their study were satisfied with the information provided to them by the nurses. They described the information that they received as being sufficiently detailed, clear and understandable. The patients in this study also perceived that the information provided by their nurses was more tailored to them compared to the information offered by the physicians, since the nurses also took account of the information that had been shared in their current and previous encounters.

Nonetheless, a previous quantitative study by Heisler and colleagues (2003) found there to be a lack of concordance between patients and their HCPs with regard to the treatment plans and strategies in real practices, which led to decisional conflict between them. Furthermore, patients who doubted the effectiveness of the treatment

plans also tended to express their dissent with their prescribed health management through non-adherence. It can also be said that there was an association between discordance and information sharing as this study also revealed discordance to be more apparent among patients with a lower level of involvement in decision-making and who had limited discussion about the decisions, in addition to among patients with a lower level of education. Nonetheless, this study found no association between the concordance and the length of the patient–HCP relationship. As long as the HCPs conducted a substantial discussion with their patients that included elements of information exchange and negotiation, there would be higher levels of concordance with regard to the planned management strategies.

2.3.3.3 Outcome of patient involvement in decision-making

Another area of shared decision-making or patient involvement in decision-making that was commonly studied in the reviewed literature was the outcomes of these approaches. Collectively, the studied outcomes of patient involvement in decision-making are related to patients' satisfaction, adherence and biomedical status (Golin, DiMatteo, Duan, Leake, & Gelberg, 2002; Franciosi et al., 2004; Jahng et al., 2005; Saba et al., 2006; Searle et al., 2008; Cvengros et al., 2009; Rahimian Boogar et al., 2013). A study by Golin and colleagues (2002) is one of the earliest of the included studies to have investigated the outcome of patients' active involvement in deciding their T2DM management. A total of 198 T2DM patients in the US were interviewed and their satisfaction was assessed quantitatively using an adapted version of the RAND-developed Patient Satisfaction Questionnaire (PSQ)-18. This study concluded that patients' perception of their physicians' facilitative behaviour with regard to their involvement in decision-making and their desired level of involvement was able to predict their level of satisfaction with their encounters with physicians.

A quite different finding from that by Golin et al. (2002) featured in an Italian study by Franciosi and colleagues in 2004. This study was conducted among 2,515 diabetes patients and looked at different aspects of the illness using a variety of

assessment tools, including patient involvement in the decision-making process (measured using four items assessing the patients' perception of the frequency of involvement), level of satisfaction (measured using the American Board of Internal Medicine satisfaction questionnaire) and quality of life (measured using the SF-36 Health Survey and the Centres for Epidemiologic Studies-Depression (CES-D)). Compared to the findings by Golin and colleagues (2002), satisfaction was found to not merely depend on the patients' desire to be involved. Rather, they proved that patients' satisfaction was dependent on the congruency of their expectation and their perceived involvement in decision-making. With no congruence between their perceived involvement and expectation, the result tended to be lower patient satisfaction with regard to their relationship with their physicians. Similar to the finding by Franciosi and colleagues (2004) is a finding from the study mentioned in section 2.3.3.1 by Cvengros and colleagues (2009), who also reported an increase in patients' satisfaction level when they perceived that their preferred level of involvement in decision-making was being attained.

A study by Jahng and colleagues (2005) also emphasised the importance of the patient and physician sharing similar preferences in terms of patient involvement in order to ensure the realisation of benefits from their collaboration in determining the most suitable treatment option for the patients. Another study with findings comparable to those of the study by Franciosi and colleagues (2004) was a grounded theory study by Saba and colleagues (2006). This study, which employed observation and interview as its methods of data collection, found that patients' satisfaction with their relationship with their physicians did not merely depend on their actual level of involvement in decision-making. There were also other factors involved, including good communication skills and a good interpersonal relationship with their physicians, as previously discussed in section 2.3.3.1.

In a study by Schoenthaler, Schwartz, Wood, and Stewart (2012), patients' satisfaction with their encounter with physicians was found to improve their adherence to the prescribed medication. Adherence is another important outcome of

patient involvement in decision-making that was studied in the reviewed literature due to the fact that T2DM involves lifelong self-management by patients away from the healthcare setting. Besides satisfaction and other factors, Schoenthaler et al.'s quantitative study involving 608 T2DM patients and 41 physicians also investigated the effect on patients' adherence of the patient–physician decision-making approach. Similar to patient satisfaction, shared decision-making or collaborative decision-making was found to significantly improve patient adherence to their diabetes medication. A similar finding was also presented by Bauer and colleagues (2014) in their survey of 1,523 diabetes patients. Bauer and colleagues (2014) found that diabetes patients who perceived themselves as not being actively involved in making a decision had lower adherence to their medication. However, both of these US studies, together with studies by Heisler, Bouknight, Hayward, Smith, and Kerr (2002) and Peek and colleagues (2008), also emphasised that T2DM patients' adherence is complex due to the fact that other factors such as social support, disease- and patient-related factors and other elements of the relationship with physicians, such as information exchange, the presence of a trusting relationship and good communication, also play an important role when it comes to adherence. Nonetheless, Schoenthaler and colleagues (2012) underlined that action should be taken to improve patient–physician interaction in order to increase the level of adherence among T2DM patients.

Based on the study by Grohmann and colleagues (2017), by being involved in the discussion about their management decision, patients expressed an increase in their levels of motivation and confidence as they felt they had the requisite knowledge and skill to perform their T2DM self-management. Furthermore, involvement in decision-making was considered to be very important among African American T2DM patients in Peek and colleagues' (2008) study. The patients in this qualitative study dealt with the different approaches to decision-making by using adherence or non-adherence. Some of the patients resorted to non-adherence as a means of regaining control over their body, while non-adherence was particularly common when their preference was not assessed and taken into consideration by the HCP in planning their T2DM management.

Cvengros and colleagues (2009) was found to be the only study that demonstrated a positive outcome of patient involvement in decision-making on their HbA1c levels, which was considered to be the main indicator of the effectiveness of T2DM management. This was especially the case when patients felt that sufficient information was being shared by their HCPs. Other studies, on the other hand, were unable to prove this, including Heisler and colleagues (2009), in which no improvement was found for any biomedical readings despite there being active patient involvement in decision-making. However, Heisler and colleagues (2009) also indicated that the preference of HCPs and self-reported practices of shared decision-making positively impacted the patients as they were more likely to provide the patients with risk factor screening tests and motivate the patients, which may have prevented them from developing diabetes complications. On the other hand, since this study involved both HCPs and patients, a comparison was possible of the preference of HCPs with regard to the decision-making approach and self-reported practices against the patients' self-reported quality of care and biomedical outcomes.

2.3.3.4 Inter-professional collaboration

Some studies have suggested that inter-professional collaboration in the management of T2DM adds another layer of intricacy to the involvement of patients in decision-making (Shortus, McKenzie, Kemp, Proudfoot & Harris, 2007; Courtenay et al., 2009; McDowell et al., 2009; Corser et al., 2010; Snyder et al., 2010; J. McDonald et al., 2012). A 2007 study by Shortus and colleagues conducted in Australia revealed a lack of information sharing between different groups of HCPs involved in the management of T2DM patients despite the Australian government's encouragement of multidisciplinary care planning in primary care. In this study, nineteen general practitioners, eight non-medical HCPs and two endocrinologists were interviewed, along with nine T2DM patients. The study indicated that care plans for T2DM patients were developed and coordinated by the general practitioners with little to no involvement from not only the patients but also other HCPs. The care plans developed by the general practitioners were usually shared with other HCPs based on their level of expertise in a particular area or type of management, typically when the

plans concerned an area with which the general practitioners were not familiar, notably when dealing with complex cases. It was also common for the general practitioners to cease sharing or referring patients' care plans with other HCPs once they had gained an understanding of those areas with which they were unfamiliar. General practitioners holding of the ultimate power to strategise T2DM patients' care plans were found to be due to their sense of responsibility to ensure the achievement of an optimal level of their patients' biomedical status, which they considered to be the most important element as it could prevent the development of complications. It can also be sensed from this study that the other HCPs, including the endocrinologists, had no issues with the fact that the patients' care plans were developed without their active involvement. Instead, similar to the patients who were indifferent with regard to their lack of involvement in the planning of their management, the non-medical HCPs seemed to be comfortable with their role as executors of the plans, while the endocrinologists worked as advisors.

Nonetheless, inter-professional collaboration was further investigated in other studies due to the importance of multidisciplinary participation in the management of T2DM. In discussing the other studies in relation to this approach to making decisions for patients, one important issue raised was that of role specification (McDowell et al., 2009; Snyder et al., 2010; J. McDonald et al., 2012). These studies emphasised the transparent and clear description of the roles for each group of HCPs in terms of both managing patients' T2DM and in making decisions regarding their treatment and management. This reflects the expanding roles of non-medical HCPs in the current management of T2DM, especially in primary care. In the study by Snyder and colleagues (2010), which explored collaboration between physicians and pharmacists in the US, it was found that to ensure the success of the collaboration, it is important that both groups mutually acknowledge the physicians' role as the main decision maker and the pharmacists as the supportive personnel or persons who are referred to with regard to patients' drug therapy. This finding is similar to the findings of the prior quantitative study by McDowell and colleagues (2009), in which there was a recognition of the different roles played by physicians and nurses despite nurses in

the UK increasingly expanding their role as HCPs who also make decisions on insulin initiation.

In discussing the role specification of each discipline in managing T2DM, however, a study by J. McDonald and colleagues (2012) reported that a lack of clarity around the roles of each discipline affected the level of trust and power dynamic in terms of sharing responsibility for the management of patients between the different HCP groups. In this Australian qualitative study, interviews were conducted with T2DM patients and various groups of HCPs involved in the management and/or prevention of T2DM, including general practitioners, medical specialists, nurses (diabetes educators, community nurses), a pharmacist, allied HCPs (dietitians, optometrists, physiotherapist, podiatrists) and other practitioners (an Aboriginal health education officer, fitness instructor and an Aboriginal community worker). It was also found that the HCPs tended to implicitly minimise their dependency on other HCPs in order to maintain their autonomy and that some of the general practitioners also limited the referral of patients to non-medical HCPs in a low-level collaboration. The study by Snyder and colleagues (2010) also reported an interweaving of the elements of trust, respect, confidence and communication when describing the practice of inter-professional collaboration. The pharmacists were reported as needing to consistently make explicit to the physicians their own contributions to improving patients' T2DM condition, in order for them to gain the physicians' trust and respect and be allowed to actively contribute their expertise to the patients' management. This reflected the physicians' role as the gatekeepers to other healthcare services for the patients.

Despite the challenges identified in the area of inter-professional collaboration, it seems that the patients perceived that they were receiving multidisciplinary care based on a considerable degree of coordination, most probably due to the established guidelines or protocols in managing T2DM (J. McDonald et al., 2012). Conversely, another study by Corser and colleagues (2010) conducted among 44 American T2DM patients discovered that the patients encountered difficulty in managing their

T2DM due to the inconsistency of the information they received and the fact that they received advice from different physicians, which was described by some patients as inadequate and fragmented. This led to patients' lack of trust in and frustration with the service that they received (Corser et al., 2010).

2.3.4 Section summary

In this part, the review has focused not only on shared decision-making but has also considered the literature on patient involvement in decision-making as a whole in order to provide a more comprehensive overview of the topic. The review of the existing literature indicates that patients have not been given sufficient opportunity to become actively involved in the making of decisions despite them displaying increased preferences to the contrary. The review has also acknowledged the importance of patient involvement in decision-making, especially in relation to chronic illnesses such as T2DM. From the discussion around patients' and HCPs' preferences on patient involvement, it can be concluded that the level varies depending on the meaning and value that a person attaches to the involvement of the patient in discussing the decision that needs to be made in order to improve their T2DM status. However, patient involvement in making the management decision and in planning their T2DM care does not depend solely on patients' preferences since it is also related to other factors, as discussed earlier.

The findings from the existing literature also support the conclusion drawn in the first part of this chapter, which described the challenge and complexity of managing T2DM, a large element of which comprises the patient's self-management. Nonetheless, in T2DM, which requires patients to self-manage and make their own decisions without the presence of their HCPs, it is important that patients become involved from the start of the management process, which is the decision-making phase, and to have comprehensive knowledge about T2DM and their health condition. It can be said that in chronic health conditions such as T2DM, patients are making two types of decision – a treatment decision in the presence of their HCP, and a management decision without their HCPs. This strengthens the need for a

mechanism that can integrate patients' needs and values with their T2DM management, which is consistent with the shared decision-making model.

In discussing the groups of participants involved in the studies, it was found that insufficient attention has tended to be paid to HCPs, despite their important role in decision-making in the healthcare system. This was evident from the number of studies conducted among HCPs being far lower than the number of studies conducted among patients. The studies that did involve HCPs focused only on certain groups, including HCPs and nurses. None of the studies was found to involve dietitians and only one included pharmacists. As the current management of T2DM is multidisciplinary, the inclusion of these HCPs may shed some light and provide a new perspective on the shared decision-making approach. There was also a lack of involvement of both patients and different groups of HCPs in discussing similar issues on the concept. In terms of the methodology and methods used, qualitative methods were employed more widely when conducting deeper exploration, especially in the Asian context where patient involvement in decision-making remains uncommon. On the other hand, despite the fact that observation may be a good additional method of collecting information when investigating the current practice of the studied topic, based on the existing literature, interviews were also found to be a good way of exploring the topic and generating a substantial and comprehensive explanation of the perspectives and experiences of the participants related to patient involvement in decision-making.

2.4 Part 3: Malaysian T2DM contextual background

2.4.1 The healthcare system in Malaysia

The healthcare system in Malaysia is a dual system involving both the public and private sectors (Jaafar et al., 2013). The public healthcare sector falls under federal government legislation and is governed by MOH Malaysia. This serves as the main provider of health services in Malaysia since it caters for majority of the country's total population, although the private healthcare sector has experienced tremendous growth over recent years. The public healthcare system in Malaysia provides a

world-class service and is equipped with the latest advances in medical equipment. Nonetheless, Malaysians pay only nominal fees for access to these high-quality services as the government subsidises them through the general taxation of income. Correspondingly, Malaysia's public health sector is characterised by limited resources, overcrowding and long waiting times, especially for specialised services. Thus, the private healthcare sector in Malaysia provides an alternative option, especially for those who can afford to pay for faster services (WHO, 2017). Apart from this, however, there is not much difference between the quality of services provided by the public and private healthcare sectors in Malaysia.

The MOH encompasses three levels of healthcare: primary, secondary and tertiary. Primary care sits at the core of the Malaysian healthcare system and serves as the first point of contact for users of the healthcare service. It provides the broadest scope of healthcare services to members of the local community regardless of their socio-economic and demographic backgrounds. The types of services offered at the primary care level in Malaysia vary from antenatal check-ups to the well-being of the elderly, and from health surveillance and school healthcare to home nursing and rehabilitation. Currently, there are 1,060 public healthcare clinics providing primary healthcare services across Malaysia (MOH 2017), with primary care physicians referred to as general practitioners, which as a category also includes medical officers and Family Medicine Specialists (FMS). Referrals to secondary and tertiary healthcare services may be made for patients depending on their needs. Secondary healthcare in Malaysia refers to the services provided in hospitals by medical officers and specialists, including general medicine, general surgery, orthopaedics, paediatrics, obstetrics and gynaecology, anaesthesiology, imaging, geriatrics and others. Tertiary healthcare covers highly specialised care across the areas of endocrinology, cardiology, cardiothoracic surgery, neurosurgery, respiratory medicine and plastic surgery, among others. To date, 144 hospitals and special medical institutions have a total of 41,995 beds for the provision of secondary and tertiary healthcare services in Malaysia (MOH Malaysia, 2017). These types of services, despite being curative and illness-focused, are expensive, fragmented and institution-based, which may be inappropriate for the majority of the public (Amar,

2004). Nonetheless, the demand for tertiary healthcare services in Malaysia has increased over the past decade due to the lack of understanding among the public and some HCPs of the importance of health assessment and prevention services (Amar, 2004).

In achieving better health services for its population and in order to meet the current trends for demand in healthcare services, there has been a remarkable increase in health expenditure, from 2.94% of the country's GDP (RM 8.2 billion) in 1997 to 4.49% of GDP (RM 49.7 billion) in 2014 (Malaysia National Health Accounts, 2014). Despite the increased budgetary allocation by the government, the MOH is challenged by the fact that the cost of providing medical and health services continues to increase year on year. In sustaining and maintaining the highest quality of care, MOH Malaysia is continuously seeking to implement cost-containment measures without adversely affecting citizens' access to healthcare. Furthermore, despite struggling to reduce communicable diseases such as dengue and tuberculosis, Malaysia has successfully reduced the prevalence of other communicable diseases, including HIV and malaria. As a result, there has been a recent shift in focus towards non-communicable diseases as its main burden. In doing this, the MOH has set its focus on preventing and controlling non-communicable diseases and their risk factors, alongside promoting lifestyle modification among the country's population in an effort to reduce the demand for costly medical interventions among the sufferers of chronic non-communicable diseases (WHO, 2017). The privatisation of the healthcare system has also reduced the government's financial burden, as consumers now cover the cost within the private sector. Additionally, with rising levels of education and awareness of patient rights, the healthcare system in Malaysia also faces increased demands and expectations from the population it serves (MOH Malaysia, 2011).

2.4.2 T2DM management in Malaysia

As a developing upper-middle-income country, Malaysia is facing economic, epidemiological, demographic and social changes which are reflected in its citizens'

way of living. Consequently, the prevalence of chronic, non-communicable diseases, including T2DM, continues to rise.

Similar to the situation seen in European and other developing countries, this alarming trend has become a major health concern in Malaysia due to the crippling medical-related complications associated with it. Studies have proven that the various micro- and macrovascular complications associated with T2DM are placing a substantial economic burden on the healthcare system, with patients requiring hospitalisation and ambulatory care and also suffering a premature death in many cases (Jönsson, 2002; Ringborg et al., 2009). Besides, recent studies indicate that a majority of T2DM patients in Malaysia, at both public hospitals (87.8%) and public health clinics (76.2%), fail to achieve optimal glycaemic control (Feisul Idzwan & Soraya, 2013; Mafauzy, Zanariah, Avideh, & Chan, 2016). This only serves to exacerbate their condition as these patients are at higher risk of developing the above-mentioned costly complications. Nevertheless, due to the fact that 80% of T2DM patients are managed in public health clinics (56%) and hospital-based clinics (24.6%) in the public health sector (Institute for Public Health, 2011), where almost 95% of the cost is financed by the Malaysian Federal Government, the adoption of better preventive measures at this ground level may work to reduce some of the avoidable costs.

In Malaysia, modern medicine has been practised since the colonial period. T2DM patients in Malaysia are managed based on the established international standard and evidence-based practice, which has been locally modified. However, diabetes is also known as ‘sweet urine’ in Malaysia, reflecting urine that attracts ants and is associated with a high blood sugar level (Ariff & Beng, 2006). Additionally, traditional forms of medicine, including Malay medicine, Islamic medical practice, traditional Chinese medicine, traditional Indian medicine and homoeopathy, are still widely practised by Malaysians as an alternative or complement to modern medicine (Ariff & Beng, 2006; Othman & Farooqui, 2015). Ching, Zakaria, Paimin & Jalalian (2013) found that 62.5% of T2DM patients in Malaysian primary care used traditional medicine when managing their condition. Despite this large percentage of

Malaysian users of traditional medicine and the emphasis being placed on HCPs to better understand the practice, there is still a lack of integration into the healthcare service of this traditional and complementary medicine based on scientific evidence (Othman & Farooqui, 2015).

2.4.3 T2DM management based on Malaysian Clinical Practice Guidelines (CPG)

In Malaysia, it is recommended that the management of all patients with T2DM is based on the CPG, as issued by MOH Malaysia. This document has been repeatedly revised and updated in line with advancements in T2DM management and the latest research findings. There have so far been five editions of the guidelines since their introduction in 1992. The main purpose of the CPG is to facilitate HCPs in their ability to properly identify, diagnose and manage patients with T2DM.

2.4.3.1 Assessment and treatment modalities

The CPG contain a set of unique treatment algorithms for Malaysian T2DM patients. These treatment algorithms cover newly diagnosed T2DM cases, clinic follow-up cases and also special cases, with the aim of improving patients' quality of life, reducing complications and preventing premature deaths. They also emphasise the need to obtain a detailed medical history from newly diagnosed patients, in addition to conducting a full physical examination. This is imperative for identifying the presence of T2DM complications and cardiovascular risk factors in terms of determining the most appropriate management regimen for these patients. For other patients, it is recommended that therapeutic decisions are made based on a full clinical, physical and psychosocial assessment, with an emphasis placed on their HbA1c level.

Diabetes education

The CPG advocate that all T2DM patients must be periodically advised and educated by their HCPs. The guidelines include self-management support and

recommendations for patients with regard to a healthy lifestyle. These include changes to dietary habits, increasing levels of physical activity, smoking cessation, medication, self-care, self-monitoring of blood glucose (SMBG) and foot care, problem-solving skills, and psychosocial adaptation, which is important in patient empowerment. All HCPs involved are responsible for educating their patients about the above-mentioned areas so that the knowledge is repeatedly reinforced. This is important as the main objectives of T2DM education are to improve patients' understanding, alleviate their anxiety and promote their self-management and compliance with the treatment.

Recognition of the importance of T2DM education has become more visible in Malaysia with the establishment of Diabetes Resource Centres (DRCs), especially in public hospitals. A number of certified diabetes educators are assigned to each centre so that as many patients as possible can be equipped with ample diabetes-related knowledge, awareness and skills.

Pharmacological modalities

Besides diabetes education for all patients, there are also patients who need extra help to achieve an optimal glycaemic level of 6.5% or below, which is the level set as the target for typical cases of T2DM in Malaysia. This is lower than the recommended 7.0% level in the USA and UK (ADA, 2017; NICE, 2015). The CPG contain a wide variety of pharmacological modalities, which are chosen based on patients' individual T2DM needs. In this treatment algorithm, it is suggested that pharmacological modalities are initiated in all T2DM patients to aid them in achieving the target HbA1c level.

Similar to the guidelines from the UK's NICE (NICE, 2015), the Malaysian CPG also recommend Biguanides (e.g. Metformin) as the first line of medication for patients who are in need. There is also a recommendation for the initiation of other oral antidiabetic (OAD) agent/s if Metformin alone is not sufficient to achieve optimum blood glucose level. These include Sulphonylureas, Meglitinides, Alpha-glucosidase Inhibitors, Thiazolidinediones (TZDs), Dipeptidyl Peptidase-4 (DPP-4)

Inhibitors and Sodium Glucose. It has previously been reported that almost all of the T2DM patients (94.1%) attending public health clinics have a prescription for at least one OAD agent (Feisul Idzwan & Soraya, 2013). This includes 27% of patients with monotherapy, 45.7% of whom are prescribed at least two OAD agents, and 16.5% of patients who receive a combination of OAD agents and insulin. Despite the increased availability of new OAD agents, including at public health facilities, Metformin remains the most commonly prescribed OAD, with 82.5% of the patients who receive this form of treatment being prescribed this sole agent of Biguanides (Feisul Idzwan & Soraya, 2013; Zanariah et al., 2015). This OAD agent has acquired and maintained its popularity due to its effectiveness not only as a monotherapy for new or uncomplicated cases of T2DM but also due to its low cost and low incidence of adverse side effects (C. J. Bailey, 2017).

Injectable agents such as insulin and Glucagon-like Peptide-1 (GLP-1) Receptor Agonist can be used as an adjunct therapy for newly diagnosed patients with high glucose levels or for patients who remain hyperglycaemic despite optimal OAD therapy. Besides, adapted from the Practical Guideline to Insulin Therapy in Type 2 Diabetes Mellitus (MOH Malaysia, 2010a), the Malaysian CPG recommend early insulin initiation among patients who struggle to optimise their glycaemic level even if they are prescribed with three oral agents, since a delay in insulin initiation often results in suboptimal glycaemic control. The use of insulin, especially human insulin, is dominant among injectable agents. This is more apparent within the realm of public health settings due to its lower cost, particularly when compared to GLP-1 Receptor Agonists (Zanariah, Sri Wahyu, Singh & Swee, 2015). It is recommended that insulin is combined with Metformin since these therapies work differently to reduce blood glucose level. Insulin dosage is titrated based on a patient's glycaemic level. There is an increasing trend in the percentage of patients with insulin prescription in both public health clinics (rising from 11.7% in 2011 to 21.4% in 2012) and public hospital clinics (rising from 54% in 2008 to 65% in 2013) (Feisul Idzwan & Soraya, 2013; Mafauzy et al., 2016).

Self-monitoring of blood glucose (SMBG)

The CPG also emphasise the importance of SMBG, especially among patients with insulin therapy, in assessing the effectiveness of their overall T2DM management and preventing hypoglycaemia. This is because SMBG readings are useful for patients when it comes to them self-managing their T2DM (Hou, Li, Qiu, & Wang, 2014).

Despite recommending that patients perform SMBG at least four times a day, the CPG also allow some flexibility with regard to its frequency based on patients' glycaemic status and goals, and their treatment modalities. Besides, in most Malaysian health facilities, patients are required to buy their own glucometer, lancet and strips, which, if they are required to test their blood glucose level four times per day, can result in significant long-term expenditure on the part of patients. Ong, Chua, and Ng (2014) also identified the high cost of SMBG as one of the barriers to SMBG practice, along with a phobia of needles and pain, patients' frustration of high blood glucose readings, and a lack of motivation, knowledge and self-efficacy. Although Diabcare studies found a significant improvement of SMBG practice among patients with pharmacological therapies in public hospital clinics, rising from 26.8% in 2003 to 58.7% in 2008 (Mafauzy et al., 2011), patients should continuously be reminded of its importance so that their T2DM can be optimally managed.

2.4.3.2 Team approach

In the Malaysian healthcare system, various professional healthcare groups are involved in the management of patients with T2DM. These include endocrinologists, FMSs, internal medicine specialists, medical officers, diabetes educators, nurses, dietitians and pharmacists. Medical officers are responsible for managing uncomplicated diabetes cases in both public health clinics and hospitals. Cases that require more advanced management and/or that involve other body systems are handled by endocrinologists at the main state general hospitals, internal medicine specialists at smaller hospitals or by an FMS in primary health clinics. Those working in the primary care setting are considered to be the first point of contact for

T2DM patients, especially medical officers. In settings where diabetes educators and dietitians are not available, they are the ones responsible for orchestrating patients' overall diabetes care, which includes lifestyle modification and patient education.

There is an increasing availability of diabetes educators, who are commonly nurses and medical assistants, in Malaysian public health facilities. This is due to the fact that they are currently no longer only to be found in the DRC of the main state general hospitals, but also in some smaller urban state hospitals and health clinics. The MOH has run a post-basic course in diabetes management since 2000, with HCPs who complete this course becoming certified diabetes educators. These diabetes educators are generally responsible for delivering diabetes education and facilitating diabetes self-management. Based on the CPG, this includes the promotion of healthy eating and physical activity, patients' self-monitoring and problem-solving, medication adherence, goal setting and risk reduction practices such as weight management, smoking cessation and adherence to medical appointments and follow-ups (MEMS, 2016). Despite this, there remains a lack of modules, outlines and regulations at the national level that can be used specifically by diabetes educators when undertaking their role in diabetes management. The sole manual specifically for diabetes educators at the national level is the Diabetes Education Manual 2016, which was published as recently as April 2016 by the Malaysian Diabetes Educators Society (Malaysian Diabetes Educators Society, 2016). Thus, many diabetes educators may still be unfamiliar with it. As a result, there is a high possibility of different diabetes educators at different locations having different responsibilities and using different intervention tools, which are commonly set by the facility's administrators or specialists.

Dietitians in Malaysia are those responsible for planning individualised dietary recommendations for patients with T2DM. Medical Nutrition Therapy (MNT) is listed in the CPG as one of the main diabetes nutrition therapies in helping patients modify their diet (MEMS, 2016). Based on the findings of a 2013 study by Barakatun Nisak, Ruzita, Norimah, and Nor Azmi, the use of MNT by dietitians in their individual consultations with diabetes patients is effective in reducing

fructosamine and HbA1c levels, especially among patients with a highly elevated HbA1c level. However, similar to diabetes educators, despite the rising number of dietitians, this is still not enough to cater for the increasing demand for their support in managing diabetes patients, especially in the primary healthcare setting.

Diabetes Medicine Therapy Adherence Clinics (DMTACs) were introduced as a way of guiding pharmacists to improve patients' medication adherence and enable them to achieve better glycaemic control (MOH, 2010b). This is in line with the role of pharmacists as outlined in the CPG. Since its introduction in 2006, this ambulatory care service has been found to have significant positive impacts on the management of diabetes patients in Malaysia. Among DMTAC patients, there has been an improvement in medication understanding and adherence which has resulted in reduced glycaemic levels, both in health clinics and hospital-based clinics (X. Y. Lee et al., 2015; Lim & Lim, 2010). On the other hand, pharmacists are also responsible for providing education related to the prescribed medications, including their side effects, to all patients with a prescription (MEMS, 2016).

The CPG also emphasise the importance of there being a collaborative effort among these different professionals in providing patients with a combination of different expertise and continuity of care. However, this may not be easy to achieve due to the multifaceted nature of the Malaysian healthcare system, which may complicate information sharing and responsibility, not only among HCPs in different settings but also within the same setting. This was proven in a study carried out at one of Malaysia's public teaching hospitals, in which a lack of continuity of care was found among patients with chronic disease due to a lack of communication between the involved HCPs, in addition to the existence of a dual medical records system (Sellappans, Lai, & Ng, 2015). This resulted in various problems, including difficulties in prescribing and managing complex medication regimens for HCPs, especially among primary care physicians, together with missing information in terms of what was received by patients.

2.4.4 Research on patient involvement in decision-making and shared decision-making in the management of T2DM – Malaysian context

The review of the existing literature focusing on patient involvement in decision-making and shared decision-making in the management of T2DM in the Malaysian context found there to be only a limited body of literature, despite this having grown in size in recent years. A study by Hwa (2005) was one of the cornerstones of patient involvement in decision-making for T2DM management in Malaysia. Although the study did not focus on the decision-making process, it did aim to investigate the preferences of T2DM patients for information in the patient–physician relationship. The quantitative study involved 105 diabetic patients from a public hospital and 50 diabetic patients from a private hospital. The patients stressed the importance of the quality over the quantity of the information provided by their HCPs. They appreciated clear and comprehensible information, especially in relation to their diagnosis and treatment. Furthermore, similar to the emphasis given by Western patients, the sense of being heard by their physician was also found to be important to the patients in Malaysia (Hwa, 2005). Thus, an assessment of patients' needs, expectations and preferences should be carried out earlier and become one of the fundamental objectives to ensure that the consultation session will not take too long and will also be worthwhile for both patients and HCPs.

Nevertheless, patient involvement in decision-making and shared decision-making in the management of patients with T2DM is a new area in Malaysia. Only a limited amount of research activities have been carried out by a small group of researchers over recent years (Y. K. Lee, Low, & Ng, 2013; Y. K. Lee, Low, Lee, & Ng, 2014; P. Y. Lee et al., 2015). All of these qualitative studies have formed part of a larger drive to create decision aids for facilitating the implementation of shared decision-making in insulin initiation for T2DM patients in Malaysia.

The initial study in 2013 by Y. K. Lee and colleagues involved 21 patients with T2DM from public and private clinics in both urban and rural areas, with the objective of exploring the values involved in the making of a decision for initiating insulin therapy. Using semi-structured in-depth interviews, the researchers identified

three main values that the patients considered to be important in deciding to commence insulin therapy. These were ‘treatment-specific values’, ‘life-goals and philosophies’ and ‘personal and social background’. The study also revealed that sociocultural and family situations influenced the decision-making process. Although the study contributed to the area of patient involvement in decision-making, it focused more on the patients’ values in relation to the treatment decision that needed to be made as opposed to their values with regard to their involvement in making the decision.

The patients’ values with regard to being involved in decision-making were addressed by the following study, conducted by a similar group of researchers (Y. K. Lee et al., 2014). Data from 22 T2DM patients were analysed qualitatively with the aim of identifying factors influencing decision-making role preferences during insulin initiation. Almost half of the patients preferred to play an active role in determining their insulin initiation, with only one patient preferring a collaborative role. The study identified five main factors: ‘trustworthiness in the patient–clinician relationship’, ‘perceived responsibility’, ‘level of knowledge’, ‘perceived family involvement’ and ‘personal characteristics’. The sole patient who preferred collaborative decision-making believed that both the patient and physician make an important contribution in making the decision on insulin initiation. Additionally, various non-medical perceived barriers were also identified, including religious beliefs regarding blood and a fear of social stigma arising from injection scars. This study also confirmed that patients in Malaysia are still not familiar with the term shared decision-making. This may be due to the use of the term collaborative decision-making as opposed to shared decision-making and the fact that the participants in the study were not provided with any vignettes.

The latest research, by P. Y. Lee and colleagues (2015), was conducted to explore the views of patients and HCPs on a patient decision aid for use in making a decision about the same topic, that of insulin initiation. The recruited HCPs were the same ones who were involved in training workshops on the use of a newly developed patient decision aid among T2DM patients requiring insulin therapy. These HCPs

then used the decision aid in their consultations with patients. At the end of the consultation, the patients and HCPs were interviewed. The study involved 13 HCPs, comprising two general practitioners, seven medical officers, three diabetes nurses and a pharmacist, along with 18 patients. The involvement of both patients and HCPs in this study allowed the researchers to analyse data from both groups. Discrepancies in the views were identified as both groups had different views on the patient decision aid being tested. The patients stated their preference for more detailed information and their appreciation for the way in which the information was given within the decision aid, which they described as direct and understandable, whereas the HCPs considered the information provided to be overly lengthy and complex for the patients to understand. Another important mismatch was detected in terms of the information that both groups considered to be important. It was found that compared to the HCPs, who emphasised the benefits of insulin, the patients wanted information related to its practicality and the impact of insulin on their day-to-day activities.

The review of the empirical studies of patient involvement in decision-making in Malaysia also found a small number of studies looking at health problems other than T2DM. These studies are elaborated in this section to provide a more comprehensive picture of this studied area in the Malaysian context. A quantitative study by Ambigapathy and colleagues (2016) was conducted among 470 adult patients visiting an academic primary care clinic, and 47 physicians. Using the Control Preference Scale, their preferences on patient involvement in decision-making were assessed. Similar to the findings by Y. K. Lee et al. (2014), it was found that the majority of the patients in this study preferred to be involved in making decisions, with more half of them (51.9%) preferring shared decision-making and another 21.8% preferring an autonomous role when it came to making their treatment decision. Nonetheless, the data collected from the physicians revealed that they were unable to recognise this and underestimated their patients' preferences with regard to active involvement.

Mah and colleagues (2016), in their study involving 210 hypertensive patients, also identified comparable findings with regard to patients' desire to be actively involved

in making a decision. In this quantitative study, the questionnaire by Bruera, Sweeney, Calder, Palmer and Benisch-Tolley (2001) was used to assess the preferences for patient involvement in decision-making. The study indicated that 51.4% of the patients preferred shared decision-making despite the fact that fewer patients (1.9%) preferred an autonomous role. Additionally, this study showed that despite most of the patients perceiving that they were informed that a treatment decision needed to be made and being presented with the available options, relatively few of them believed their opinion and preferred option were taken into consideration. This finding demonstrated that the physicians continued to make decisions paternalistically despite their effort to share information with their patients.

Y. K. Lee and colleagues (2015) conducted a study on patient involvement in decision-making from the perspective of HCPs managing patients with localised prostate cancer. Focus group discussions and interviews were conducted among 20 physicians and government policymakers. The findings indicated that the HCPs had different views on the role of HCPs in determining a treatment option for prostate cancer patients. There were some HCPs who believed they should be the ones making the decision based on an assertion that this was their patients' preference, which was actually an erroneous assumption on their part, as also found in another study by P. Y. Lee and colleagues (2015). Nevertheless, this study showed that there were some HCPs who viewed themselves as a guide and facilitator for the patients and their families in terms of their role in determining the most suitable treatment option for them.

2.4.5 Section summary

Malaysia, as a developing country, has a good healthcare system and has also developed its own guidelines for managing T2DM. In reviewing the research activities, only a limited number of studies have been conducted in exploring and investigating patient involvement in decision-making and shared decision-making in Malaysia. The majority of these studies found patients who preferred to be actively involved in deciding their treatment option despite the complexity of the process and the traditional paternalism that has long been embedded within the Malaysian

healthcare system. Among these studies, only three looked at T2DM, with the focus on the development of decision aids for insulin therapy initiation. It was also found that despite there being two studies involving both patients and HCPs, only one of these included diabetes nurses and a pharmacist among its participants. Thus, a study that further and more deeply explores patient involvement in decision-making and shared decision-making in the overall management of patients with T2DM from the perspective of not only patients and physicians but also other HCPs will contribute significantly to a more comprehensive and wider context.

2.5 Chapter summary and areas for further exploration

This chapter began with an overview of the philosophical underpinning of patient involvement in making decisions about their T2DM treatment and management. Based on patient-centred care, shared decision-making has encouraged the popularity of patient involvement in their T2DM decisions since it was first introduced in 1997 by Charles and colleagues, owing to its proven effectiveness. Nonetheless, due to a lack of consistency in its conceptual underpinning in different contexts, its integration into practice and the measurement of outcomes has been challenging.

The second part of this chapter reviewed existing empirical studies surrounding patient involvement in decisions, which include shared decision-making on T2DM care. The review focused on the perceptions and experience of the stakeholders with regard to patient involvement in decision-making, including shared decision-making itself. This was carried out as shared decision-making is considered to be the narrower or arguably ideal model of patient involvement in decision-making, yet it may not be familiar to a wider audience, especially for those who have not yet been introduced to the model. Thus, a review of the studies in the wider context of patient involvement in decision-making was more sensible in terms of producing a more comprehensive explanation of this component of patient-centred care. On the other hand, an exploration of views and experiences is still important as the foundation of the implementation of any new concept into practice.

Overall, it is clear that the involvement of patients in decision-making remains poor despite the acceptance of patient-centred care and the realisation of its importance and benefits. The preferences of the participants with regard to the practice, as one of the most explored areas in shared decision-making, also vary depending on the value that they place on being involved in decision-making. It was also found that patient involvement is heavily dependent on the patient–HCP relationship and the characteristics of HCPs as the gatekeepers to healthcare services. Paternalism continues to be very apparent and most of the time still plays an important role in patient involvement in decision-making as patients' opportunity and intention for becoming involved still depend greatly on their HCPs. Nonetheless, this may also be due to the fact that there was a lack of exploration of this matter among HCPs as compared to patients. This is especially the case among pharmacists and dietitians who are considered to be the groups that are actively involved in the management of T2DM.

Finally, despite the emphasis on the importance of stakeholders' understanding and values pertaining to patient involvement in decision-making in different cultures and contexts, not many studies were found exploring these elements in either Asia or in Malaysia specifically. This type of exploration is considered to be fundamental in shaping the measures and plans in the implementation of shared decision-making in this part of the world that has significantly different cultural and social backgrounds. The exploration of the same issues in the management of T2DM in Malaysia resulted in the discovery of three papers that mainly described one project on shared decision-making intervention using decision aids focusing on insulin therapy initiation. However, there is still a lack of basic understanding of both patients' and HCPs' views on their experience of, and the factors related to, patient involvement in decision-making and shared decision-making in the overall management of T2DM.

Thus, the completion of this chapter has highlighted the need for a study that explores the views not only of patients but also of different groups of HCPs in producing a more comprehensive overview of the current status of patient

involvement in decision-making related to T2DM in the Malaysian context. This is because, as a relatively new approach to fostering the involvement of patients in decision-making, the model or framework and measurement instruments, including measurement of the process, outcome and the surrounding elements of shared decision-making, need to be continuously developed and improved. This is in order to demonstrate the effectiveness of the approach, especially in the management of chronic diseases including T2DM among people from different sociocultural backgrounds. Thus, the findings of this research will help the researcher to understand the perspectives of patients and HCPs in the comprehensive management of T2DM and may also contribute to the future development of a shared decision-making framework in the Malaysian context. With the empirically grounded findings of this approach, it is hoped that a better outcome may be achieved so that patients with T2DM will have a better quality of life and better overall health outcomes.

2.6 Statement of the research problem

Over the last three decades, patient involvement, also known as patient participation, has been one of the central issues of research focusing on patient autonomy in the healthcare system. However, due to its complexity and an overall lack of clarity, the concept has tended to be addressed with little more than 'tokenism' by HCPs (Roberts, 2002). This may be partially attributable to the fact that each patient and HCP may have his or her own opinions or ideas about the meaning and implementation of patient participation in disease management (Sahlsten et al., 2008).

Patients with T2DM run an elevated risk of developing dangerous complications such as nephropathy, neuropathy, retinopathy and other cardiovascular problems, if the disease is not properly managed. Patients are required to deal not only with the decision-making process with their HCPs but must also decide on their daily activities. This may seem minor, but the decisions that are made also have a greater effect on patients' overall health, including on decisions regarding the type of food they consume, medication adherence, physical activity, smoking or drinking habits and any other related behaviour (Ming et al., 2011). Thus, shared decision-making

may contribute significantly to a patient's empowerment, which in turn will lead to good decisions being made by the patient, even in the absence of their HCPs, especially with regard to decisions pertaining to their own self-care and self-management (Bodenheimer et al., 2002).

Shared decision-making, as mentioned earlier, is one of the approaches that encourage patient participation in the decision-making process as it relates to the patient's illness. However, the same trend of patient involvement in terms of a lack of clarity has also been found for this concept. Shared decision-making has been described, interpreted and implemented differently across the academic literature, especially across various cultural and social contexts (Peek et al., 2008; Mead et al., 2013; Obeidat, Homish, & Lally, 2013; Ahmad et al., 2014; Shay & Lafata, 2014). This is because every person has their own views and values regarding what is important to them in implementing shared decision-making in practice (Goold, Williams & Arnold, 2000; Sahlsten et al., 2008; Y.K. Lee et al., 2014). These views and values are based primarily on people's social, cultural and religious beliefs, which can give rise to different views, expectations, needs and preferences regarding the shared decision-making approach (Thelen, 2005; van Kleffens & van Leeuwen, 2005). Furthermore, there is evidence of incongruities between patients' understanding of the shared decision-making approach and how it is conceptualised by the theorists and researchers (Entwistle et al., 2008; Peek et al., 2008; Shay & Lafata, 2014).

Besides, even though patient involvement in decision-making and shared decision-making has been widely researched and incorporated in healthcare systems, particularly in Western countries, a review of the topic in Malaysia has shown that incorporation and research of the concept and approach are scarce (Ng et al., 2013). The transfer of conceptual understanding from one cultural and social context to another will therefore not necessarily be effective (Charles, Gafni, Whelan, Ann & Brien, 2006), especially when Malaysia has a distinctly different social and cultural background compared to Western countries. Thus, an extensive exploration of the understandings and views of the people involved is needed in order to investigate its

suitability and to ensure it can be successfully accepted and become effective in the long run. A deeper and more thorough understanding of this matter is crucial so that a comprehensive model or framework for incorporating shared decision-making into diabetes management in the Malaysian healthcare system can be designed and operationalised.

2.7 Personal reflections on the research problem

My personal interest in the area of decision-making for diabetic patients was sparked after I first encountered a patient with uncontrolled T2DM who, despite having had diabetes for more than three years, was still unclear about his own health problem and the treatment he was receiving. As a result, most of the time he merely attempted to adhere to his recommended management, and most of the time he found himself in a difficult situation where he did not know what to do and then chose to simply abandon his prescribed treatment and the advice given to him. Further conversation with the patient revealed that most of the decisions and related information were both made and given by HCPs, without any effective discussion between them. After some time, I realised that other patients were also experiencing the same problem as this particular patient. Throughout my literature search exploring these two worrying conditions, I came to realise that they were likely to be related. From the literature, it is found that involving T2DM patients in decision-making may help to improve their knowledge about their health condition and management, develop their self-efficacy in managing their illness and at the same time improve their quality of life. However, the amount of information in this area remains very limited, especially in the Malaysian context. Therefore, I developed a very strong interest in exploring shared decision-making as one approach to encouraging patient involvement in making their treatment and management decisions.

CHAPTER 3: METHODOLOGICAL ISSUES AND RESEARCH DESIGN

3.1 Introduction

Chapter 1 of this thesis highlighted the worrying trends in and impact of T2DM all over the world, including in Malaysia. Involving the patient in decision-making has been encouraged as a means of both improving T2DM management and meeting the needs of the contemporary health landscape, where increasing value is being placed on patient participation in decision-making. As such, shared decision-making was introduced 20 years ago to facilitate this effort. Chapter 2 further demonstrated the lack of information on patient involvement in T2DM decision-making, in both the Malaysian and wider Asian contexts. This has created uncertainty as to whether the existing shared decision-making models and interventions, which are mostly derived from Western culture, are transferable to Malaysian patients. As such, the perspectives of the different stakeholders who are directly involved in managing the illness in this part of the world should be explored in order to gain a comprehensive understanding of their experience and understanding of patient involvement in T2DM decisions. To address the chronic nature of T2DM, where the patients are the ones that need to carry out the decisions made during the clinical encounters, this study focuses on T2DM management in the outpatient setting. Consequently, the information gathered from this study can help to develop a more appropriate policy and practice that is tailored to Malaysian needs.

This chapter begins by outlining the research aims and questions. It then proceeds to discuss the philosophical basis of the qualitative research design. The data collection strategy is also explained, together with the data analysis process, related ethical considerations and questions of validity and reliability. Finally, the chapter presents my reflexivity as the researcher along with the limitations of the study.

3.2 Research aims

This study aims to explore the perspectives and experiences of patients and HCPs with regard to patient involvement in decision-making in the management of T2DM in Malaysia.

3.3 Research questions

In the Malaysian healthcare system:

1. How do patients and HCPs experience patient involvement in decision-making for the management of T2DM?
2. How do patients and HCPs view shared decision-making for the management of T2DM?
3. What are the factors related to patient involvement in decision-making for the management of T2DM?
4. How can shared decision-making be operationalised in the management of T2DM?

3.4 The research paradigm

A paradigm can be defined as *"... the basic belief system or worldview that guides the investigator"* (Guba & Lincoln, 1994: p. 105). In determining the paradigm of this study, thoughtful deliberation was carried out with regard to a number of critical considerations. This was done to ensure that the selected paradigmatic approach would direct the study to achieve its aims since the paradigm strongly influences the ontology, epistemology, theoretical perspective, methodology and methods of a study (Guba & Lincoln, 1994; Crotty, 1998; Lincoln & Guba, 2000).

The first important consideration was that this is an exploratory study since its focus is on building an understanding of the meanings, along with their construction, that are ascribed to patient involvement in decision-making and shared decision-making,

which also typically further relates to the participants' attitude and behaviour in making decisions concerning the management of T2DM. Next, it is also crucial to acknowledge and incorporate the understandings and views of heterogeneous groups from different backgrounds that are directly involved in the management of T2DM so that the topic of interest can be explored holistically. Besides, as the act of decision-making in T2DM predominantly involves interaction between these groups, the social aspect of the meaning-making is also considered in depth.

Since T2DM is a chronic health problem that requires patients to meet regularly with their HCPs in respect of its ongoing management and treatment, combined with the fact that HCPs meet different types of patients, it is common for the meanings ascribed by both patients and HCPs to change over time in line with new interactions and experiences. This forms another important consideration for this study. By contrast, this study also aims to identify the need for change so that recommendations for practice can be made accordingly. Lastly, an acknowledgement of my contribution to the study as the researcher is also relevant due to the fact that I was a nurse who previously managed inpatient T2DM patients. Despite having been involved in a slightly different context from that of this study, my background interest and position nevertheless had great potential to impact upon the study process. This is further explained in the Reflexivity section in 3.11.

3.4.1 Paradigm, ontology and epistemology

Based on the critical considerations presented in 3.4, the paradigm best suited to this study is constructivism. Constructivism is also predominantly chosen due to the alignment of its aims with the aims of this study. It allows the researcher to address the complexity of humans and their interaction with their social surroundings and environment (Miles & Huberman, 1994).

This paradigm also acknowledges that there is no one absolute true reality, since reality is created through one's social, cultural and experiential process (Guba &

Lincoln, 1994). Multiple realities and meanings are put forward by the different individuals involved in the study with regard to certain situations, and these are extensively explored and valued in this paradigm (Creswell, 2008). This is also known as relativism, which serves as the ontology of constructivism (Patton, 2002; Creswell, 2008). The concept of having multiple realities fits well with this study as it embraces the contribution of participants from diverse groups so that a comprehensive understanding of how they view and understand social interaction and the world can be achieved. The participants in this study are not only situated at two different ends of the healthcare system, with patients as the receivers and HCPs as the providers, they also have different sociocultural backgrounds and stages of disease progression in the case of the former, and different roles in managing T2DM patients for the latter.

The justification for selecting constructivism as the paradigm of this study is further strengthened as it supports the changes in patients' and HCPs' views on patient involvement in decision-making that occur over time. This is because T2DM is a chronic disease that requires patients to continually consult their HCPs. The advantage of using constructivism over other paradigms is that it enables further exploration of the implications of the cognitively and emotionally constructed meanings of the individuals with regard to their attitudes, actions and interaction with others and the world (Patton, 2002). This is again important in the context of T2DM as a chronic condition for which patients need to make decisions outside their consultation sessions with their HCPs.

In preserving the complexity of the realities and meanings that emerge from the data collected, Creswell (2008) emphasised the importance of the role of the researcher in addressing these rich findings and not merely categorising the views into only a few themes. They have to go beyond this in order to gain a deeper and more extensive understanding of the topic being studied. This is also done to address the epistemological stance of the constructivist paradigm, which concerns the subjectivity of findings that arise from multiple realities.

Despite the advantages it offers, constructivism has also been criticised for its exclusion of any critical sense of the construction of social and cultural meanings (Crotty, 1998), especially when compared to other research paradigms and epistemologies such as social constructionism and feminism. As explained earlier, the social and cultural element cannot be separated from this study as it is considered to be one of the main elements in the decision-making process due to the fact that it involves interaction between at least two people. Besides, critical sense in conducting empirical studies will guide researchers to comprehend and change the underlying orders of social life which commonly relate to power (Foucault, 1978). Thus, in addressing this issue, symbolic interactionism and the work of Bourdieu on practice and power relations were used to guide further exploration of these critical issues that were found to be greatly and inevitably related to the studied topic. Further explanation of these theories can be found later in this chapter.

3.4.2 Theoretical perspectives: Interpretivism and symbolic interactionism

3.4.2.1 Interpretivism

In constructivism, people play an active role in the construction of meaning based on their interpretation of the social reality (Patton, 2002), and this is aligned with interpretivism. Based on the following description of interpretivism by Blaikie (2000), the adoption of this theoretical perspective assists in the building of a sophisticated understanding of the influence of the meaning and value attributed to social interaction and experience concerning patient involvement in decision-making and its related factors at the individual level.

> *"Interpretivists are concerned with understanding the social world people have produced and which they produce through their continuing activities. This everyday reality consists of meaning and interpretations given by the social actors to their actions, other people's actions, social situation, and natural and humanly created objects. In short, in order to negotiate their way around their world and make sense of it, social actors have to interpret their activities together, and it is these meanings, embedded in language, that constitute their social reality."*

In addition, the role of the researcher in constructivism is not only as an information processor. As presented in the critical consideration of this study in the earlier subsection of 3.4.1, the researcher is acknowledged as the active generator and constructor of the context alongside the participants (Guba & Lincoln, 1994; Charmaz & Belgrave, 2014). This is similar to the roles played by researchers under interpretivism. Schwandt (1994) suggested that interpretivism is concerned with the contribution of the investigators to the process of meaning construction, in addition to being concerned with the method and matter of knowing and being of the people.

3.4.2.2 Symbolic interactionism

To further address the social construction of meaning, symbolic interactionism, as one of the primary strands of interpretivism, was chosen to further guide this study. The outcome of the decision to use symbolic interactionism in this study is evident throughout the Findings and Discussion chapters.

Symbolic interactionism by Blumer (1969), which originally emerged from the work of George Herbert Mead (1863–1931), enunciates the close relationship that exists between the action of an individual towards people or situations and the meanings they ascribe to those particular people or situations; it cannot thus be isolated from the society and culture. Symbolic interactionism also focuses on language, thought, meaning, shared symbols and social acts (Boden, 1990). It can thus be seen that symbolic interactionism and constructivism complement each other as both emphasise the construction of the meaning and action of individuals, in addition to addressing the contribution of social interaction to the construction of social meaning (Blumer, 1969; Charmaz & Belgrave, 2014). Blumer (1969) also included words, gestures, rules and roles as the main symbols that are present and which play an important part in normal everyday human interactions.

The patient–HCP partnership is given as one of the most important elements in shared decision-making and also predominantly depends on the parties' engagement, relationship and interaction with each other during their encounters (Charles et al., 1997; Coulter, 1997; Towle & Godolphin, 1999). In addition, the social reality and environment of both patients and HCPs contribute significantly to these meanings (Rapley & May, 2009). As quoted from Patton (2002: p. 132), the central question of symbolic interactionism is *"... what common set of symbols and understandings has emerged to give meaning to people's interactions?"* Thus, symbolic interactionism is particularly relevant in exploring the experience and meanings of patient involvement in decision-making as it allows the researcher to discover not only the meanings and interpretation that both patients and HCPs ascribe to their experience, interactions, actions and situations, but also how these meanings have developed differently in the Malaysian context by incorporating a different social and cultural background from that of the Western context, where shared decision-making has already been introduced to facilitate patient involvement. In addition, this theoretical perspective acknowledges 'rituals in social life' (Crotty, 1998: p. 77), which are considered to be the common belief of the reality. This is especially important in this study as it will help me to make sense of the common belief in relation to the permissible acts within the study context.

Decision-making in the management of T2DM as a chronic disease is an iterative process that involves long-term relationships and interactions between the patients and HCPs within the healthcare system. By using symbolic interactionism this phenomenon is properly addressed, as Blumer (1969) emphasises that meanings are moulded and modified over time by individuals' social interactions. One of the reasons that this happens is due to a change or improvement in individuals' capacity to interpret and construct social reality (Patton, 2002). Therefore, symbolic interactionism helps to form a deeper and more comprehensive understanding of the decision-making behaviour and views of both patients and HCPs, and its link with the above-mentioned concepts and symbols by Blumer (1969). Charmaz (1990) also asserts that symbolic interactionism triggers questions relating to why participants think, feel and act the way they do. 'How do their constructions of the meaning

develop and change throughout their illness?' Charmaz also highlighted how symbolic interactionism is concerned with the contribution of one's beliefs, feelings and actions to these constructions, and the further consequences of these constructions. This further helps me to interpret and present arguments pertaining to the causal relationships among the data gathered on shared decision-making, which is considered to be one of the main aims of qualitative research (Mason, 2002).

Nevertheless, symbolic interactionism is labelled as 'pragmatism in social attire' (Crotty, 1998: p. 62), and this serves to further frame this study. Pragmatists believe that problems can usually be addressed by understanding the function of thinking in humanity's adjustment to the environment (Hammersley, 1989). It is also considered as 'a tool for action', and from this perspective, there will always be an association between people's knowledge of the concept and its practicality in the real world (Cornish & Gillespie, 2009: p. 802). Thus, there should be a flow of research enquiries aimed at a resolution of the human problem, which in this case is the lack of effective management of T2DM and an understanding of the patients' and HCPs' perspectives of a new interventional model that may improve management of the disease.

3.5 Research Methodology

This study aims to explore and understand patient involvement in decision-making and shared decision-making since knowledge of this topic has not been extensively and fully developed, especially in the context of the management of diabetes in Malaysia. A direct adoption of the available Western model of shared decision-making, which was introduced to facilitate the involvement of patients in decision-making, will probably not be a good fit for the needs and situation in this study context.

A qualitative research method was considered to be the best design for this study as the objective is to explore the meanings that the participants ascribe to their

experience of involving patients in decision-making, their preferences, expectations of shared decision-making and the reasons behind these (Charles et al., 1999; Paley & Lilford 2011). This is also aligned with the paradigm chosen for this study. By using a qualitative method which is naturalistic in nature, the researcher is able to develop a deeper understanding of the topic of interest as it explores not only how the participants conceptualise patient involvement in decision-making and shared decision-making but also enables the researcher to identify the process and related factors and to discover unforeseen phenomenon (Maxwell, 1996; Patton, 2002).

3.5.1 Qualitative research method

Based on the symbolic interactionism view, in gaining an understanding of the meaning and experience of shared decision-making, the interpretations and meanings that the study participants attribute to their experience (actions and interactions) and the context need to be explored (Crotty, 1998). Thus, the chosen method should allow the researcher to hear the participants' points of view expressed in their natural context, with only minimal alteration of the study sites and no prior limitation of the output. The qualitative research method was thus chosen for this study as it helps to facilitate this kind of exploration (Lincoln & Guba, 1985; Bowling, 2009).

Qualitative research has a history dating from the early twentieth century and rests on the epistemological bases of George Herbert Mead's symbolic interactionism and Florin Znaniecki's analytic induction. It became a new interest during the 1920s and 1930s as researchers identified the need for a new method to explore human behaviour and thought, which are complex and irreducible to simplified and fixed patterns (Hammersley, 1989). These characteristics thus increase the suitability of the adoption of a qualitative research method in exploring the complex idea of patient involvement in making decisions related to the management of T2DM. In addition, Bowling (2009) also strongly recommends that qualitative researchers explore the cause-and-effect relationship of the topic of interest. This is because they have better access to the type of rich and in-depth information that is required, including people's experience, perceptions and opinions, feelings and understanding

and knowledge, despite the approach's lack of ability to test causal hypotheses. This is in parallel to the explanation of interpretivism by Bryman (2016) regarding the valuable contribution of the qualitative method in providing an interpretive understanding of causal explanations of human behaviour.

Since its introduction, work has continuously been carried out on qualitative research methods not only to address the criticisms laid on them by other methods, but also to provide qualitative researchers with scientific or empirical guidelines. The basic or original qualitative research method itself has been labelled using other terms such as interpretive, basic (Merriam, 2009), generic and descriptive qualitative research (Sandelowski, 2000; Caelli, Ray, & Mill, 2003). This is due to the development of other methodological variants following the development of the original qualitative method throughout the years. Among the famous qualitative methodological variants discussed extensively by Creswell (2007) in his book *Qualitative Inquiry and Research Design* are grounded theory, narrative study, case study, ethnography and phenomenology. Nevertheless, due to its alignment with the main aims of this research and its epistemological basis, the basic or generic qualitative research method was chosen. However, for the purpose of this study, it is termed as an interpretive qualitative research method as this matches the theoretical underpinning of the study. The following subsections will further explain why this method was selected over other major qualitative research methods.

3.5.2 The rationale for choosing the interpretive qualitative research method

The interpretive qualitative research method was adopted for use in this study to assist me as the researcher in understanding patient involvement in decision-making as a whole. Supporting the epistemology and theoretical perspective of this study, the selection of the qualitative research method allows me to capture and interpret the subjective element of the participants. The overall interpretation of the data helped in exploring the participants' perspectives and practice in relation to shared decision-making and how this is cognitively and emotionally constructed based on the attribute of their experiences and the world that they are in (Merriam, 2009).

Nevertheless, even though a range of quantitative instruments have been used to study patient involvement in decision-making, these instruments are likely capable of eliciting only limited information, and this may not be locally and culturally sensitive (Clayman & Makoul, 2009). The interpretive qualitative method enabled the researcher to hear directly from the patients and HCPs regarding their preferences and expectations of shared decision-making, and why these were important to them.

The use of the qualitative research method, not underpinned by any specific philosophical framework such as grounded theory, ethnography or phenomenology, is also reasonable to use in exploring the topic of interest as it was proven to be useful in various studies with similar aims that were conducted in other contexts (Peek et al., 2008; Shay & Lafata, 2014; Jull, Giles, Boyer & Stacey, 2015). It has also proven to be valuable in exploring the possibility of different understandings of the concepts despite the existence of a significant number of available theories of shared decision-making (Lim, 2011). This is especially true where shared decision-making has not yet been introduced, despite patients' involvement in deciding their T2DM management being encouraged and valued. This corresponds with the situation at all of the study sites.

Nowadays, more and more research in the health and social science field employs a qualitative research approach that is not underpinned by any specific philosophical framework (Sandelowski, 2000; Caelli et al., 2003). The interpretive qualitative research method enabled the researcher to extract useful elements from the other variants that fit with this research at the same time as maintaining flexibility in answering the research questions in the context of the contemporary world (Kahlke & Hon, 2014; Bryman, 2016). However, this is opposed by Silverman (1994) who made the traditional assertion that different methods of qualitative research should not be specified as a general approach and combined freely. Nevertheless, according to Thorne, Kirkham and MacDonald-Emes (1997), the utilisation of a credible interpretive qualitative method is useful for developing clinical knowledge when it is combined with relevant health/nursing/medical science.

This clinical knowledge, which encompasses an understanding of how people view and experience the health problem, can be further used in the strategic development of measures for improvement.

It is common for the interpretive qualitative method, which is also regarded as a basic qualitative method, to be labelled the *'crudest form of inquiry'* (Thorne et al., 1997: p. 170) due to its lack of theoretical structure. However, according to Sandelowski (2000), there should not be a hierarchy when it comes to describing different types of methods as these methods are employed based on their potential to answer the research questions in hand. In dealing with this criticism, this study has employed elaborate theoretical foundations including constructivism and symbolic interactionism, as explained earlier in section 3.4.

Despite grounded theory being one of the qualitative research methods that could have been used to address the research questions of this study since it aims to conceptualise social reality and its implication for human behaviour, its main focus is the development of a theory (Petty, Thomson, & Stew, 2012; Charmaz, 2014), which is not the main objective of this study. In contrast, as was laid out earlier in subsection 3.4.1, one of the main underpinning considerations of this study is to accurately represent the meaningful experiences and understanding of patients and HCPs. There is the potential for this not to be properly addressed using grounded theory as the data selected as being relevant to the development of the theory tend to be abstract in nature and are usually removed from the participants' accounts (Holloway, 2005). Compared to the theoretical sampling conducted in grounded theory with the aim of developing a theory (Glaser & Strauss, 1967), this study's purposive sampling method focuses more on the recruitment of diverse groups who are directly involved in the management of patients with T2DM.

Nevertheless, in this study, the data were analysed concurrently during the data collection and constant comparison processes, a practice which is more common in grounded theory (Glaser & Strauss, 1967; Charmaz, 2014). This was carried out to

enable further exploration of the emerging themes at the same time as ensuring that all of the data collected were systematically compared to all of the other data in the data set and not overlooked (Pope, Ziebland, & Mays, 2000; O'Connor, Netting, & Thomas, 2008).

Another research method that is popular in qualitative studies looking at patient involvement in decision-making is ethnography. According to Hammersley and Atkinson (2007), ethnography can be described as an approach that *"... involves the researcher participating, overtly or covertly, in people's daily living for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts – in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry"* (p. 3). The adoption of ethnography is useful as it enables the observation of an interview with the participants to be conducted in their natural setting and the context in which the behaviours of concern are practised. However, the decision-making process involved in chronic health problems, including in T2DM, is not a one-off event but rather is distributed across people, places and time. This requires rigorous observation of not only multiple medical and health consultations but also the observation of patients' decision-making processes outside consultation times, yet this may be considered to be too intrusive to both patients and HCPs. Besides, the information needed to answer the research questions and to achieve the main objective of this study can be collected through in-depth qualitative interviews with heterogeneous participants, thereby avoiding any unnecessary disruption to the everyday lives of the participants.

Case study is another qualitative research method that was reviewed for its potential as an approach for this study, as it aims to *"... develop a complete, detailed portrayal of some phenomenon"* in a particular context (Schwandt & Gates, 2018: p. 346). The researcher is required to collect data from multiple sources, including in-depth interviews, participant observation and document review, to achieve a comprehensive understanding of the participants' views and experiences. As

mentioned earlier in reference to the unsuitability of ethnography, this is not necessary for this study. Besides, similar to the assertion by Creswell (2007), it was difficult to identify the case/cases of this study, and this may have led to even more challenging implications in the later process of the research.

3.6 Research methods

This section describes in detail how this study was carried out. It includes the sampling strategy, data collection method, data analysis, ethical considerations and issues related to validity and reliability under the topic of rigour.

3.6.1 Sites of the study

This study was conducted at government-funded health facilities based on the fact that the majority of patients with T2DM in Malaysia attend these facilities for their T2DM management and follow-ups (Institute for Public Health, 2011). Two health clinics (SC and CC) and one medical specialist clinic (HC) at a hospital were selected. All of these health facilities are situated in the urban area of the Federal Territory of Kuala Lumpur and Putrajaya, which is centrally located in Peninsular Malaysia. These study sites were selected in order to meet the aims and objectives of this study within the time and resources available.

Besides being located in urban areas, which are found to have a slightly higher prevalence of diabetes in comparison to rural areas in Malaysia (Letchuman et al., 2010; Institute for Public Health, 2015), the sites were also selected for their ability to provide the maximum variation of participants. SC and CC are situated within high-density areas that are home to residents with a broad range of backgrounds and socio-economic characteristics. On the other hand, HC was chosen due to the status of the hospital as a tertiary endocrine referral centre, thereby enabling the recruitment of patients with different progressions of T2DM from those that could be recruited at the health clinics. Due to its status as a referral centre, HC primarily manages complex T2DM cases from other governmental health institutions,

including primary health clinics and other hospitals, private practitioners and walk-in patients that require more advanced and comprehensive management, in addition to its own T2DM patients discharged from wards. Patients with different backgrounds are referred from all over the area, and this makes a significant contribution to the study, not only by providing data for different layers of T2DM outpatient management but also by enabling the recruitment of patients from a wider range of sociodemographic backgrounds and T2DM progression and management. The inclusion of HC benefits this study as the outpatient management of T2DM in Malaysia also includes the hospital's medical/endocrine clinics. Its inclusion thus provides a greater and more comprehensive picture of the management of T2DM in the outpatient setting in Malaysia.

There are differences in the management of T2DM across these different settings. SC and CC are among Malaysia's 1,060 public health clinics that serve as the first point of contact for health services in Malaysia. Both clinics are divided into two main divisions: an outpatient clinic (primary care service), and a maternity and child health clinic (maternity and child health service). Despite this, the clinics are led by one FMS, and both divisions share the same resources. Both SC and CC are equipped with basic imaging and laboratory facilities, and a pharmacy. The outpatient clinics receive new or walk-in cases, patients who have been discharged from hospitals and follow-up cases presenting with various medical problems. The management of T2DM at SC and CC is fairly similar and involves an FMS, medical officers, nurses, pharmacists and dietitians. Both of the clinics also have a diabetes team that is responsible for the organisation and management of any activities related to diabetes in the clinics. Compared to HC and CC, the management of T2DM in SC can be considered as basic, as it only recently moved to its current location. Despite having a diabetes team, it is yet to be fully functioning for the same reason. The diabetes-related programmes were still in the planning stage at the time the data collection for this study was carried out. Nonetheless, aside from a dietitian, there is also a nutritionist on duty at this clinic to further support its provision of diabetes care.

At CC, besides having a staff nurse who is also the diabetes educator (referred to as a diabetes nurse educator in this current study), the clinic runs programmes aimed at improving the management of patients with diabetes, which is something not yet available at SC. These programmes include a diabetes management group comprising different HCPs who are responsible for the management of T2DM at the clinic. The group comprises an FMS, several medical officers, a diabetes nurse educator, a dietitian and several pharmacists. The programmes include group-based diabetes education and health education seminars. CC has also introduced personalised care to improve the management of patients with chronic disease, including T2DM. Under this scheme, T2DM patients see the same medical officer at each medical follow-up, thus ensuring continuity of care for their chronic illness.

HC, as the specialist medical clinic in a hospital, sees the greatest variety of T2DM cases among the study sites and offers a wide range of services for these patients. Hence, more HCPs are involved in the management of T2DM at this site compared to the other study sites. These include endocrinologists, medical officers, diabetes educators (nurses and medical assistant), pharmacists and dietitians. In this clinic, endocrinologists manage diabetes patients together with medical officers. This hospital also provides diabetes consultation through their DRC. Four diabetes educators (three nurses and one medical assistant) are assigned to provide diabetes education and support for patients in managing their T2DM in their everyday life. The aim is for all new patients, especially those who are prescribed insulin, to be referred to this centre so that they can be equipped with the sufficient knowledge, skills and tools to carry out all of their T2DM self-management, especially insulin self-administration and self-monitoring of blood glucose. This centre receives 100 to 200 patients each month (new and follow-up cases), 70% of whom are referred from the hospital's specialist medical clinic. Similar to SC and CC, this clinic and its DRC run an appointment-based system for the scheduling of patient visits. Follow-ups for the DRC are given to patients, ranging from every two weeks to monthly based on their ability to control their glycaemic level, whereas meetings with physicians take place ranging from every month to four to six months. Besides physicians and diabetes educators, patients are also referred to the dietitians, pharmacists and wound

management team for further diabetes counselling and consultation. Different activities and programmes are also organised at this site to support their diabetes patients, including an obesity clinic, group-based diabetes education and health education seminars. The variety of management of T2DM across the selected sites was useful for capturing a more comprehensive level of data for this study.

3.6.2 Sampling strategy

As the main aims of this study are to explore the views and experiences of T2DM patients and HCPs, the study used purposive sampling to recruit both patients and HCPs. This sampling technique is used widely in qualitative research as it enables the identification and selection of participants who are in a good position to provide rich information and in-depth insights into the area of interest and, most importantly, the research aims, and not merely for the purpose of generalisation.

In addition, the adoption of purposive sampling enabled a diverse range of patients to be selected based on their social background (age group, gender, ethnicity and social classes) and T2DM characteristics (length of time diagnosed with T2DM, T2DM progression, trend of diabetes control, severity of T2DM and treatment trajectories). For the HCPs, this sampling method permitted different groups of HCPs within each facility to be recruited and represented (Bowling, 2009). Thus, the data from a heterogeneous sample could be explored, thereby increasing the richness of the data and enabling maximum variation of the participants and a comprehensive exploration of the topic of interest (Ritchie, Lewis, & Elam, 2003). Throughout the six months of data collection (November 2015–April 2016), a total of 43 participants with different backgrounds and roles in the management of T2DM in the study sites were successfully interviewed. A further breakdown of the participants is given in subsection 3.6.2.1 and 3.6.2.2.

3.6.2.1 Recruitment of the patients

The records of patients who attended their medical appointments during the data collection period were reviewed. Discussion was held with the HCPs, who serve as the immediate gatekeepers of the patients, thus ensuring the eligibility of the patients. Some of these gatekeepers also put forward a number of recommended patients as they had already been briefed on the details of the study and the inclusion and exclusion criteria. The patients' records were further reviewed to ensure their eligibility and fit with the needs of the research.

The patients were selected based on the inclusion and exclusion criteria listed below:

Inclusion criteria:

- Patients with T2DM
- Patients aged 18 years and above
- Patients who are able to communicate in Malay or English
- Patients who are willing and able to provide informed consent
- Patients who are willing to discuss and share information.

Exclusion criteria (determined from a patient's records or discussion with the gatekeeper):

- Patients determined as having a cognitive impairment or learning disability through discussion with the HCP in charge
- Patients with a diagnosis of depression that had a high possibility of being exacerbated through their participation in the interview
- Patients with type 1 diabetes mellitus
- Patients below 18 years of age
- Patients not fluent in either Malay or English
- Patients who were not willing to provide informed consent
- Patients who were not willing to discuss and share information.

The selected eligible patients were subsequently approached individually, and an explanation of the study was provided. A participant information sheet was distributed during this initial briefing session. The contact details of the potential participants were obtained, and they were contacted within 24 hours to enquire as to their willingness to participate in this study. A cooling-off period of 48 hours was given to the potential participants to provide them with an opportunity to reflect on their decision. For those who agreed to participate, the interview session, date, time and venue were arranged based on the participants' availability and convenience. Nonetheless, almost all of the patients who agreed to participate preferred to be interviewed on the same day that they indicated their willingness to participate. Informed consent was obtained from the participants prior to the interview session. Figure 4 provides a summary of the recruitment strategy for the patients. At the end of the data collection stage, 7 patients from SC, 7 from CC and 10 from HC, thus making a total of 24 patients, were successfully interviewed. Further details about the participants can be found in *Table 2*.

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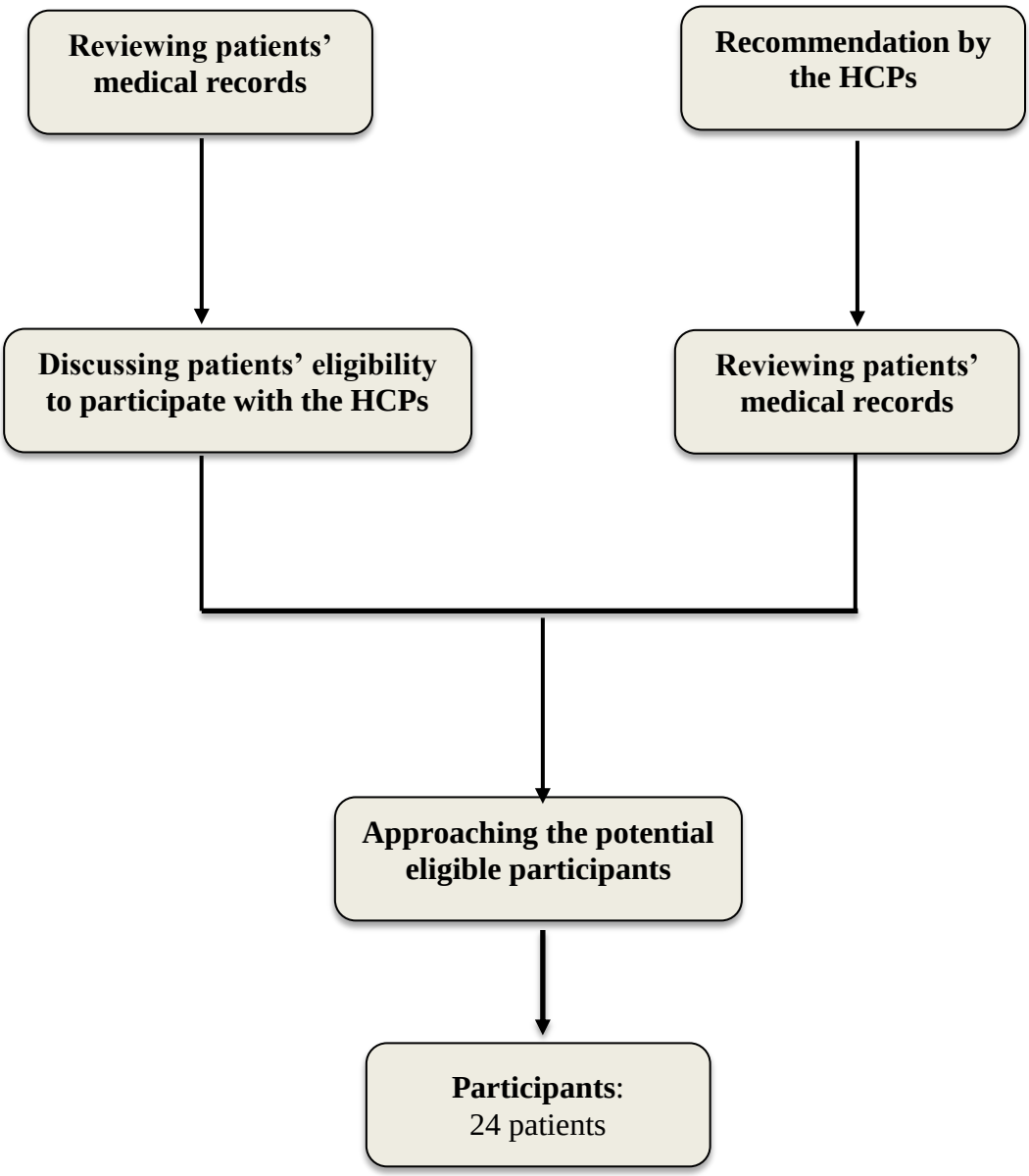

Figure 4: Recruitment strategy of patients

Table 2: Characteristics of T2DM patients

Participants' ID	Establishment	Age	Gender	Ethnicity	Education level	Duration with T2DM	Current T2DM treatment
PT1	SC	82	Male	Malay	Form 3 secondary school	1.5 years	Oral Metformin
PT2	SC	61	Male	Indian	PhD	10 years	Insulin Actrapid, Oral Metformin
PT3	SC	70	Female	Malay	Standard 4 primary school	15 years	Insulin Actrapid
PT4	SC	62	Female	Chinese	Standard 4 primary school	4 years	Oral Metformin
PT5	SC	71	Female	Indian	Form 3 secondary school	6 years	Oral Metformin
PT6	SC	54	Female	Malay	Form 3 secondary school	10 years	Insulin Actrapid
PT7	SC	47	Female	Malay	Form 3 secondary school	6 years	Insulin Actrapid, Novorapid & Insulatard, Oral Diamicron
PT8	HC	61	Male	Malay	Certificate	30 years	Insulin Actrapid, Novorapid, Insulatard
PT9	HC	70	Male	Malay	Bachelor	11 years	Insulatard
PT10	HC	35	Male	Malay	Bachelor	6 months	Insulin Mixtard
PT11	HC	36	Female	Malay	SPM (Form 5 secondary school)	4 years	Oral Metformin

Participants' ID	Establishment	Age	Gender	Ethnicity	Education level	Duration with T2DM	Current T2DM treatment
PT12	HC	29	Female	Malay	Diploma	6 months	Janumet & weight management
PT13	HC	48	Female	Indian	SPM (Form 5 secondary school)	11 years	Insulin Novarapin, Insuman & Oral Metformin
PT14	HC	33	Male	Chinese	Bachelor	3 years	Insulin Actrapid & Oral Metformin
PT15	CC	59	Male	Malay	Form 3 secondary school	15 years	Oral Metformin, Glibenclamide
PT16	CC	57	Male	Chinese	Bachelor	4 years	Oral Metformin, Glibenclamide
PT17	CC	58	Male	Indian	Bachelor	12 years	Insulin Insulatard & Oral Metformin, Gliclazide
PT18	CC	55	Female	Malay	SPM (Form 5 secondary school)	1 year	Oral Metformin, Gliclazide
PT19	CC	50	Male	Malay	SPM (Form 5 secondary school)	10 years	Oral Metformin, Gliclazide
PT20	CC	54	Female	Malay	SPM (Form 5 secondary school)	16 years	Oral Glibenclamide & Oral Acarbose
PT21	CC	66	Male	Malay	Standard 3 primary school	9 years	Insulin Insulatard & Oral Metformin, Glibenclamide

Participants' ID	Establishment	Age	Gender	Ethnicity	Education level	Duration with T2DM	Current T2DM treatment
PT22	HC	34	Female	Malay	Diploma	4 years	Insulin Mixtard
PT23	HC	61	Male	Malay	SPM (Form 5 secondary school)	16 years	Insulin Actrapid & Oral Metformin, Janumet
PT24	HC	44	Female	Malay	SPM (Form 5 secondary school)	10 years	Insulin Actrapid, Insulatard & Oral Galvus

3.6.2.2 Recruitment of the HCPs

A series of meetings was held with the unit managers/administrators, and a list of recommended professionals who are actively involved in the making of decisions in relation to the management of T2DM patients was obtained. This list included nurses, who make up the majority of the diabetes educators, a medical assistant, who is also a diabetes educator, dietitians, a nutritionist, pharmacists, medical officers, consultants and a specialist. The sampling was done to ensure that each HCP group was represented. The potential HCPs were approached individually. Details regarding the study were explained and an information sheet was provided for their reference. Additionally, the same time frame of 24 hours was given for them to consider their participation, along with a 48-hour cooling-off period. Similar to the procedure with the patients, for HCPs who agreed to participate, the interview session, date, time and venue were arranged based on their availability and convenience. Informed consent was obtained from those who agreed to participate. *Figure 5* contains a summary of the recruitment strategy for the HCPs, and a total of 19 interviews were conducted with HCPs. *Table 3* provides the characteristics of the HCPs that were recruited.

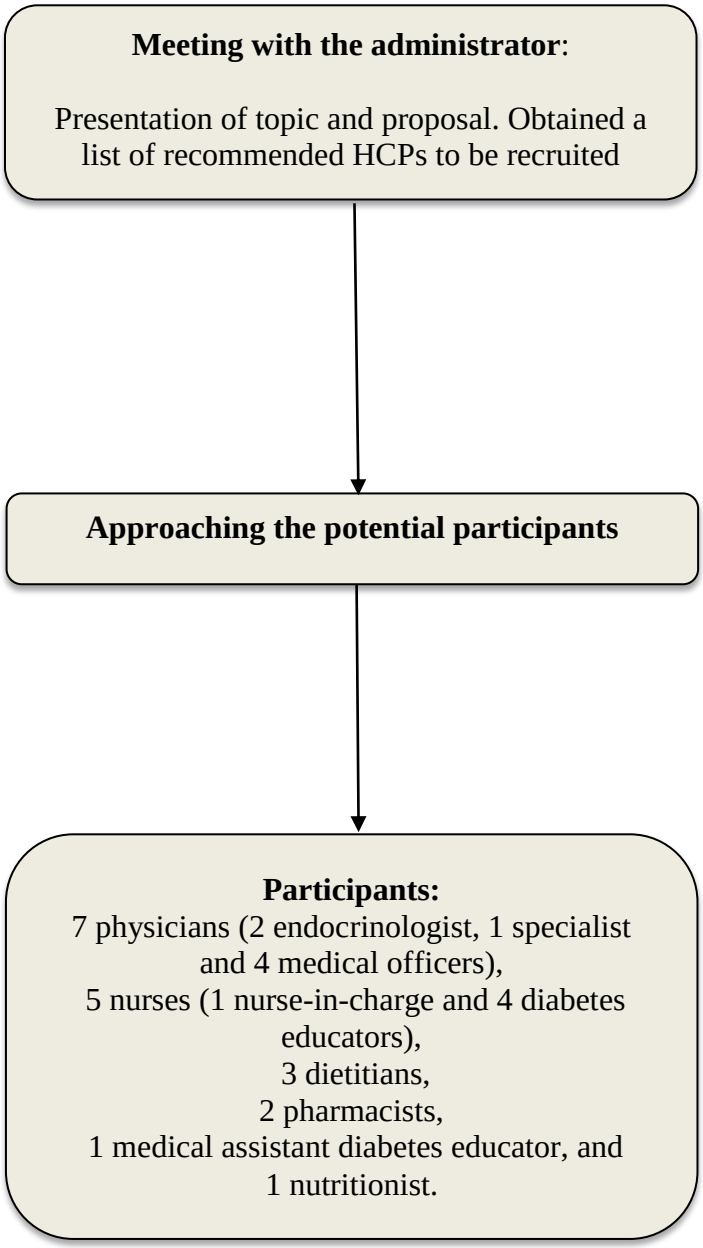

Figure 5: Recruitment strategy of HCPs

Table 3: Characteristics of HCPs

Participants' ID	Establishment	Age	Gender	Ethnicity	Occupation	Years of working with T2DM
HCP1	SC	55	Female	Indian	Staff nurse	20 years
HCP2	SC	28	Female	Malay	Nutritionist	2 years
HCP3	SC	25	Female	Chinese	Pharmacist	2 years
HCP4	SC	28	Female	Malay	Dietitian	3 years
HCP5	SC	33	Female	Malay	Medical officer	3 years
HCP6	HC	38	Female	Malay	Diabetes nurse educator	6 years
HCP7	HC	35	Female	Malay	Diabetes nurse educator	6 years
HCP8	HC	44	Female	Malay	Diabetes nurse educator	10 years
HCP9	CC	31	Female	Chinese	Pharmacist	8 years
HCP10	CC	29	Female	Malay	Dietitian	6 years
HCP11	CC	28	Female	Malay	Medical officer	1 year
HCP12	CC	39	Female	Indian	Medical officer	2 years
HCP13	CC	37	Female	Malay	Diabetes nurse educator	5 years
HCP14	HC	30	Male	Malay	Medical assistant (Diabetes educator)	1 year
HCP15	CC	47	Female	Indian	Family medicine specialist	10 years
HCP16	HC	34	Female	Malay	Dietitian	10 years
HCP17	HC	33	Male	Chinese	Medical officer	8 years
HCP18	HC	40	Female	Malay	Endocrinologist	20 years

Participants' ID	Establishment	Age	Gender	Ethnicity	Occupation	Years of working with T2DM
HCP19	HC	50	Female	Malay	Endocrinologist	20++ years

3.6.3 Data collection method

3.6.3.1 In-depth interviews

The main aim of the study is to gain an understanding of human beings in their social environment, which was achieved by exploring the views and experiences as perceived by the people involved in the management of T2DM. In alignment with this aim and the philosophical stance of this study, in-depth interviewing was considered to be the best method of enquiry (Mason, 2002; Brinkman, 2018).

> *"What is distinctive about interpretive approaches, however, is that they see people, and their interpretations, perceptions, meanings and understandings, as the primary data sources. Interpretivism does not have to rely on 'total immersion in a setting' therefore, and can happily support a study which uses interview methods for example, where the aim is to explore people's individual and collective understandings, reasoning processes, social norms, and so on."* (Mason, 2002, p. 56)

The in-depth interview also provided the opportunity for me to probe and question extensively in response to each participant and their individual experience, perspective, behaviour and context (Arthur & Nazroo, 2003). Based on Blumer's (1969) enunciation of symbolic interactionism, humans' perceptions and the meanings that they attach to their experience change over time. This is more significant in this study due to the fact that a decision relating to the management of T2DM as a chronic health condition is not a one-time event (as mentioned earlier in section 3.5.2). Thus, an in-depth interview was considered to be the best means of capturing all of the information required by this study as it enabled a comprehensive and detailed exploration based on not only one particular time, which would serve to limit the observation. Compared to a focus group discussion, the in-depth interview was more useful for this study as it allowed for an exploration of the key issues

among all of the participants in addition to a discussion of sensitive issues, which is very significant to the topic of decision-making (Kaplowitz, 2000).

Face-to-face interviews were conducted with the patients in either a private room/area at the respective clinics or at another location near to the clinics, as per the wish of the patients. The HCP interviews were conducted either at their office or a private room at the respective clinics, based on availability. Prior to the interview and after written consent had been obtained, details about the participants were collected. A separate form was used to record all of the required details, which was important in analysing and understanding the data. Different forms (Appendix 5) were used for the patients and HCPs, as different details were required for each of these two groups. Each interview was also audio-recorded with the permission of the participant. Two devices were used to record each interview in the event that one did not work as planned. The interviews were conducted in either Malay or English based on the participants' preference and lasted for between 30 and 90 minutes.

For this study, face-to-face in-depth interviews were conducted with the participants based on the topic guide, as given in Appendix 5, to ensure that the relevant issues in regard to the studied social phenomenon were covered and the research questions were answered (Arthur & Nazroo, 2003). The interview guide was created based on the key elements as listed in the integrated model of shared decision-making by Makoul and Clayman (2006). Basically, all of the participants were asked about their experience of the decision-making process, their role in determining their management and their views and expectations of shared decision-making. The interviews employed open and broad questions in relation to the overall perspectives of the participants from their subjective accounts. Aside from this, the interview sessions were conducted in a sufficiently flexible manner to allow the key topics and issues to be covered in the order most suited to each participant, thereby allowing the participants' responses to be fully explored and the researcher to be responsive with regard to unanticipated issues raised spontaneously by the participants, in addition to enabling any new issues to emerge (Arthur & Nazroo, 2003).

3.6.3.2 Interview transcriptions

Although verbatim transcription of audio recordings can be considered as a straightforward task (J. Bailey, 2008), the transcribing of 43 interview recordings was also a time-consuming process. Thus, the process was carried out by me with the help of two other hired transcribers. However, to ensure accuracy and to provide context to the transcriptions carried out by the transcribers, I carefully listened to the recordings again and compared them to the transcriptions. This re-listening of all of the transcriptions was crucial in enabling me to become familiar with the data and to pick up on any details that had been missed during the transcribing process.

3.6.3.3 Translation

A total of 32 out of the 43 interviews (74.4%) were conducted in Malay, with the remaining 11 in English. According to Wong and Poon (2010), there has been a lack of debate on translation issues in cross-cultural qualitative research in general, not to mention, more specifically, on the appropriateness of the translating method used in the study. However, the decision was made to translate all of the Malay transcriptions into English prior to the detailed analysis process being carried out. All analysis was done of the English transcripts. This was primarily because it allowed me to share the translated interview transcriptions with my non-Malay-speaking supervisors. This sharing was imperative in order to increase the credibility of this qualitative study, as suggested by Creswell (2007). This is especially crucial given the fact that I am a novice qualitative researcher and have required close guidance by the supervisors in analysing the collected data and to assist me in not missing any useful details. In addition to the 11 interviews in English, the interviews conducted in Malay were rich in information and also worth sharing with the supervisors, thus reinforcing the decision to translate the Malay interviews into English. Equally, it has to be acknowledged that the conducting of analysis in only one language can reduce any risk of confusion as it results in the use of codes in only one language.

In comparison with the transcribing process, I opted to translate all of the Malay transcriptions into English myself, as I am familiar with both of the languages.

Despite being as time-consuming as the transcribing process, this decision was made as I realised that an appointed professional translator may not be able to accurately capture the true meaning of the language used by the participants merely from the transcriptions (Harrington & Turner, 2000). In addition, having only one translator in a study can ensure consistency of translation, thereby ultimately increasing the reliability of the translated documents (Twinn, 1997). It is also believed that having all of the Malay transcripts translated by myself, as the person who conducted all of the interviews, helped to ensure better translation, especially when words or phrases could be translated in several different ways or where there was no direct English translation. The translating process also helped me to become more immersed in and closer to the data. Nikander (2008: p. 226) emphasised that *"... practical compromises are typically made between the ideals of faithfulness to the original, the readability and accessibility of the final transcript, as well as time and space issues"*. In addition, this study does not employ discourse analysis, where the concern is very much focused on the language.

Nevertheless, a number of measures were taken to ensure the trustworthiness of the translated texts. The structure of the patients' speech in Malay was maintained as far as possible to ensure there was no alteration to the meaning. A further step taken to preserve the trustworthiness of the study was to maintain a fluid description of those words that did not have an exact equivalent in English (van Nes, Abma, Jonsson, & Deeg, 2010). For these words, the Malay word or phrase was included immediately after the translated word or phrase to enable it to be easily referred to if needed. The translated text was also positioned in the box next to the original Malay text up to the end of the analysis stage in a bid to reduce the possibility of misanalysing, following a recommendation by Nikander (2008). In a bid to further reduce bias, the translated texts were also shared and discussed with two other qualitative researchers who understand English and Malay, as recommended by Filep (2009).

3.6.3.4 Notes

Notes detailing the session were also documented for each interview. These included information about the physical setting of the sessions, details of the interaction during the interviews and reflections on the information received in the sessions (Patton, 2002). However, this information was not analysed; instead, it was used as a reflexivity tool to assist in the data analysis as it helped to recall certain events that were important and was also helpful for planning the subsequent interviews (Patton, 2002). Even though the data analysis of this study was done concurrently, the notes from the previous interviews helped me to plan ahead for my next interview.

3.7 Data Analysis

Qualitative data can be analysed in many ways, including thematic analysis, framework analysis, discourse analysis or narrative analysis. The data in this study were analysed using thematic analysis with the incorporation of the constant comparative method. The data analysis for this study was conducted while the data collection was still in progress. This helped my thinking process to revolve around the existing data and prevented me from amassing huge volumes of superficial data. The following data collection was carried out based on the strategies that were generated from the earlier data analysis, which allowed for the gaps in the data to be filled (Miles & Huberman, 1994).

3.7.1 Thematic analysis

Thematic analysis was used in this study as it allowed the researcher to systematically identify common meanings and patterns within the data collected from a significant number of participants, which then resulted in the emergence of themes (Sandelowski, 2000; Guest, Macqueen & Namey, 2012). Thematic analysis is an analytical approach that is commonly linked to generic qualitative study. It is considered to be one of the most frequently used methods of analysis in qualitative study as it offers wide-ranging flexibility (Braun & Clarke, 2006) despite the claim that it lacks ‘identifiable heritage’ (Bryman, 2016: p. 584) and transparency (J. Smith

& Firth, 2011). Loffe and Yardley (2004) further highlight how the strengths of thematic analysis lie in its combination of the systematic treatment of data, the development and refinement of themes and the possibility of contextualising them. Besides, this type of analysis also shares the inductive qualities of grounded theory but does not necessarily lead to the creation of a theoretical model, which is not the aim of this study (Guest et al., 2012).

All of the above-mentioned reasons reinforced the decision to use thematic analysis over other types of analysis such as phenomenological analysis, which has the aim of capturing the uniqueness of the participants' narratives as co-constructed with the researcher, or discourse analysis that focuses on the use and meaning of language, which was not congruent with the main aim of this study (Patton, 2002; J. Smith & Firth, 2011).

The thematic analysis in this study involves six phases of analysis based on Braun and Clarke (2006), and these are illustrated in *Table 4*. A further explanation concerning the adoption of this method for analysing the study data is given in 3.7.3.

Table 4: Flow of thematic analysis method (Adopted from Braun and Clarke, 2006)

No	Stage	Description of the process
1.	Familiarisation	Transcribing data, translating the Malay transcription, repeated reading of the data and identification of initial ideas
2.	Generation of initial codes	The data were gathered into codes, which were generated systematically during this stage
3.	Search for themes	The generated codes were then gathered to identify the emerging themes
4.	Reviewing the emerging themes	The themes were checked to ensure their relation to the coded extracts and the entire data set to generate a thematic map

No	Stage	Description of the process
5.	Defining and naming the themes	The themes and overall story that the analysis tells were further refined to generate clear definitions and names for each theme
6.	Producing the report	The final stage comprising the selection of vivid, compelling examples relating the analysis back to the research question and literature to produce a scholarly report of the analysis.

3.7.2 Constant comparative method

In ensuring that all of the data were analysed and systematically compared with all of the data in the data set, constant comparative analysis was carried out in conjunction with thematic analysis (Lincoln & Guba, 1985). The use of constant comparison means that patterns across and variation between the participants' accounts can be determined (Glaser and Strauss, 1967). Although Glaser and Strauss (1967) describe the main purpose of the constant comparative method as the construction of a theory from the ground up, the method was employed despite this not being the main aim of the study as it helped to provide an explanation and perspective of the behaviour of the participants in their natural environment (Glaser & Strauss, 1967; Thorne, 2000). In addition, according to Charmaz (2014), constant comparison can help the researcher assess how each participant in the study understands their situation.

Fram (2013: p. 20) argued that the adoption of constant comparison outside grounded theory is beneficial to *"... maintain the emic perspective and how theoretical frameworks maintain the etic perspective throughout the analysis"*. In-depth interviews provide thick description from the participants, who are also known as insider(s). This served as the emic perspective in this study and was maintained by using constructivism, plus symbolic interactionism, as the foundation of the qualitative study. The integrated shared decision-making model by Makoul and Clayman (2006) was used to explore the patients' involvement in decision-making versus the existing models that are beneficial in encouraging this in practice.

Bourdieu's work on practice and power relations was used as an interpretive theoretical framework for exploring those factors that had a relationship with the related behaviours at the abstract level (Charmaz, 2006). Both of these were used to maintain the etic perspective in my study and enabled me as a novice researcher to explain and discuss the social phenomena of the study (Fram, 2013). The value and support of a theoretical framework and literature review to empirical qualitative research is also emphasised by Charmaz (2006; p. 165), outlined as helping the researcher to position their findings in the existing knowledge and also to determine how their findings can 'extend, transcend, or challenge' the main ideas in the field of study.

Contrary to the traditional assertion by Glaser and Strauss (1967) in terms of describing a constant comparison regarding literature exploration, in this study the literature review commenced at the beginning of the research project. The carrying out of a review of the literature both before and during the data analysis helped me as a novice qualitative researcher not only contextualise the study within the existing knowledge and but also to further explore the topic of interest by looking at the cause-and-effect relationship or 'mutual shaping' of the interactions and actions related to patient involvement in decision-making (Lincoln & Guba, 1985; Strauss & Corbin, 1990; Creswell, 2007). However, in maintaining my openness to the emerging themes, the theoretical framework which served as the analytical tool for this study was determined in the middle of the data analysis, based on the findings that emerged from the inductive analysis of the data. According to Charmaz (2009), this analysis is known as abduction in the constructivist framework.

This study follows Lincoln and Guba's (1985: p. 340) adoption of Glaser and Strauss's constant comparative method in the exploration and construction of relationships from data, a process also known as *'mutual shaping'*. Lincoln and Guba (1985) acknowledge Glaser and Strauss' four steps of constant comparative analysis: comparing incidents applicable to each category, integrating categories and their properties, delimiting the theory, and writing the theory. However, similar to this study, their implementation of constant comparison does not include the theory

development steps and is limited to the data processing aspect of constant comparative analysis.

3.7.3 Integration of thematic analysis and constant comparative analysis

As the data collected in a qualitative study are thick and rich, I need to be familiar with all of the data sets. As such, data analysis commenced with me repeatedly listening to the audio recordings and re-reading the interview transcripts so that I could be immersed in all of the data that I had collected (Braun & Clarke, 2006). This was done for all of the data sets of both patients and HCPs concurrently. Apart from that, I also verbatim transcribed almost half of my interview recordings, re-reading and comparing the transcripts against the original audio recordings, and translated all of my Malay transcripts into English. Despite being time-consuming tasks, all of these were crucial in further facilitating me to become familiar with the flow of the data and to identify common similarities or differences and to discover the potential patterns that could be generated (Bowling, 2009; Braun & Clarke, 2006). Thus, during this stage, notes were taken on the theoretical and methodological memos, and also my personal insights, so that they could be referred back to in the later stages of the study. As the study's data analysis was carried out concurrently with the data collection, some changes were made to the interview topic guide based on the analysis of data that had been carried out earlier. These included further explanation of the topic and inclusion of the new topics that had emerged from the previous interviews.

Initially, I planned to analyse the data sets from the patients and HCPs differently, believing that the experiences discussed by the patients and HCPs would be different. However, as I interviewed the patients and HCPs and became familiar with the data from both groups, it became apparent that most of the time there was an element of crossover within the respective discussions. For example, the HCPs' experiences and perceptions were drawn from a wide range of experiences involving different patients requiring discussion about different decisions based on their T2DM problem. Similarly, the patients also described their experiences of dealing with different

HCPs in managing different problems related to their T2DM. As a result, in many instances, the data from both groups generated similar, if not the same, codes. In addition, since the interviews with both of the groups were conducted concurrently, it was reasonable for the data analysis that was started during data collection to be done concomitantly. Thus, the decision was made to merge the analysis for the patients and HCPs.

Next, line-by-line coding was carried out for the entire data sets using NVivo 10. This was done with the intention of condensing and labelling the data so that they could be organised in a more systematic and meaningful way (Saldaña, 2010). Each unit of data was labelled with a unique code, with most of the codes being used repeatedly in the analysis of other data sets as all were found to contain common areas of discussion. According to Braun and Clarke, (2006: p. 88), *"… coding will, to some extent, depend on whether the themes are more 'data-driven' or 'theory-driven'"*. The coding began in a more data-driven manner as the entire content of the data sets was coded. By doing this, all of the data sets from all of the participants were given equal attention and repeated patterns were identified across the data. Yet, as Makoul and Clayman's (2006) integrated shared decision-making model was used as the base model of the shared decision-making approach in this study, some of the related data were coded around some of the elements that were listed in this integrated model. Due to this, in many instances, one unit of data was given more than one code, which Braun and Clarke (2006) describe as a common occurrence. Throughout the coding process, the data sets and codes were shared with the supervisors for review. This was done to support the trustworthiness of the study process and the emerging findings, as discussed in subsection 3.10.3.

Constant comparison was carried out in all stages of the data analysis. It was done in a recursive manner, moving back and forth between the emerging codes and the data, and between the newly emerging codes and the previous codes. By doing this, similarities, differences and salient patterns were identified within the data. Similar codes addressing similar concerns were then grouped together under one category or

theme. The continuous comparative process further helped me to maintain my emic perspective of the data at the same time as triggering and guiding me to find the description and characteristics of the categories (Lincoln & Guba, 1985). This is described as the step of integrating the categories, which are referred to as themes in this study, with their properties.

Based on the thematic analysis, the analysis of the data progressed as the themes were identified, reviewed and named (as described in *Table 5*). *Table 5* provides an example of the themes that emerged from the codes. In this study, the properties were identified and their connection with the themes was explored and built based on the participants' narratives (constant comparative analysis), theoretical memos and also from the existing literature (Fram, 2013; Charmaz, 2014). The theoretical memos are the records of my analytical thinking that facilitated me in making connections between the abstract ideas for the gathered data and the concrete details of the evidence. This is in line with the assertion by Glaser and Strauss (1967) that memo writing is necessary in the constant comparative method in order to build a description and interpretation of the emerging themes. As such, the memo is crucial in tracking the development of the relationship between the ideas or themes and also to uncover the properties of the themes (Roulston, 2008). Thus, by engaging in theoretical memo writing during the data analysis phase of this study, an integrated understanding of the empirical data obtained from the interview sessions could be developed and the relationship between the categories could be examined. At this point, I attempted to generate my initial thematic maps as a visual representation of my interpretation of the data, with the maps being continually modified and updated as the data analysis progressed.

However, my supervisors and I then established the need for a social theory to further facilitate my analysis and help me make sense of the data. This theory would serve as my theoretical framework and enable me to conduct deeper exploration of the characteristics of the emerging themes and produce a better explanation of the association not only between the themes and their characteristics but also between

the overall themes. After much consideration, Bourdieu's work on practice and power relations (further explained in section 3.7.4) was chosen for use as a theoretical framework to further analyse the data due to its compatibility with the emerging themes and also with symbolic interactionism as the theoretical perspective of this study. Subsequently, all of the data sets, codes and themes, and their properties, were again reviewed and compared in a more theory-driven approach, so that a cohesive explanation could be produced for the mass of data that had been collected.

Furthermore, even though the analysis of the data from the patients and HCPs was conducted at the same time and not separated, any similarities and differences were presented and discussed in the subsequent Findings and Discussion chapters. This was done with a selection of quotes representing both the patients and HCPs so that the presentation and discussion of the data was carried out not only on an individual and also a larger collective basis, but also to enable opinions from both groups to be presented and discussed in a more meaningful way, which is parallel to the theoretical underpinning of this study. Despite the fact that both groups discussed most of the categories, occasional categories included extracts from only one group, as only that group had spoken about it. Subsequently, further discussion on the reason for this occurrence was entered into. All of this material can be found in the following Findings and Discussion chapters. As qualitative research is very much concerned with the preservation of the natural language of the participants, I tried not to make any amendments to the selected quotes.

Table 5: An example of emergent themes from codes

Transcripts	**Codes**	**Theme**
"But sometimes…for example for SMBG, actually they have to do it everyday but because of the cost, every strip cost RM 2, so it depends to the patients. It would be enough if they can do it 3 times per week." HCP8	**HCPs' flexibility**	**Deliberation and negotiation**
"Yes, maybe because they are afraid of renal failure and all. They get that from surrounding and not from our medical practitioner. When they tell us that, we'll try to convince them back. All the medication that been prescribed and provided by MOH are tested and researched ones, and it's already been approved and proven. Furthermore, we'll do blood test and if the medication is not suitable for them, we'll discontinue it and change to other available medication." HCP14	**Justifying the recommended option by medical evidence**	
"And what i do sometimes is the one that is 50-50 whether they want to take it or not, I try to bargain with them, "okay, aunty, I'll give like 2 weeks you try first, and if you can't do it, it's fine I'll off it and we can again some other time."" HCP5	**Convincing patients to try the recommended option**	
"Actually about the suggestion by the private doctor, I did ask the doctor here, "can I try this medication?" He said okay, if I am brave enough to try. Try it for one month, and see whether it will help or not, and if not, I should stop." PT24	**HCPs allowing patients to try their preferred option**	

3.7.4 The background to Bourdieu's writing on practice and power relations

The preliminary analysis of the collected data resulted in the identification of several key aspects in relation to the patients' involvement in decision-making. These included the characteristics of the patients and HCPs, social and cultural aspects, and patient–HCP power dynamic/power relations. At this point, I began to look for existing literature to serve as a conceptual analytical tool in navigating the complex data, so that all of the key aspects could be further explored in more detail. A qualitative research method is a method that allows pragmatic consideration in addressing the issues of uncertainty in conducting research (Patton, 2002). Thus, the decision to adopt Bourdieu's work during the analysis process is acceptable in qualitative research as it is believed that it will generate outcomes that are more meaningful as it helps the researcher to *"… move beyond basic description to in-depth description, interpretation and explanation"* (Kelly, 2009: p. 286).

3.7.4.1 Habitus, capital and field

Habitus

Habitus is one of the most prominent and multi-layered concepts introduced by Bourdieu. In his book *Outline of a Theory of Practice*, habitus is defined as:

> *"… the durably installed generative principle of regulated improvisations, produces practices which tend to reproduce the regularities immanent in the objective conditions of the production of their generative principle, while adjusting to the demands inscribed as objective potentialities in the situation, as defined by the cognitive and motivating structures making up the habitus."* (Bourdieu, 1977: p. 78)

It can thus be summarised that an individual's attitude, perceptions, beliefs and knowledge are generated through principles or dispositions known as habitus that is moulded by past history and experience, thought process and motivation. This subsequently contributes to the individual's practice. Despite comprising embedded

and durable principles, habitus can be changed or fixed, although this does not happen easily. Adjustment will occur as needed in a situation or over a long period of time as the situation or the world evolve (Navarro, 2006). Both embodiment and adjustment occur without being noticed by individuals, and they are often ignored. Habitus is also inclined to govern an unconscious practice as the objective potentialities subdue conscious calculation (Bourdieu, 1990). It has been used to form an immediate plan of action when facing a probable future. This plan will serve as guidance for things to either do or not do, or to say or not say, in generating the desired results.

People as agents are also tied to their social world, as habitus is 'the internalisation of externality' and 'the externalisation of internality' (Bourdieu, 1977; Bourdieu, 1990). It is common for individuals from the same social class to have similar practices as they tend to share the same basic notions and principles (including social norms, rules, obligations and laws), which often serve to standardise the way they think, feel and respond (Von Scheve & Von Luede, 2005). A similar background history or objective conditions among a social class serve to form a unitary objective meaning among its members. The personal preference and style of each social member are collectively generated for these reasons. As a result, it is often the case that an individual's personal intention and practice are taken for granted (Bourdieu, 1990). Nevertheless, for these reasons, Bourdieu denied that homogeneity of practice is a product of obedience.

Field

Besides habitus, field is another concept that is taken into account as it provides a current context, structure and/or practical sense to habitus, which results in a more relevant practice (Bourdieu & Wacquant, 1992). Bourdieu's work on the notion of field began with his discussion of the social structure and class which are located in the field (LiPuma, 1993). The social structure in the field consists of positions occupied by social agents. There are internal and power dynamics within social structure resulting from the different distributions of power between different social

positions in the field. Consequently, fields, according to Bourdieu, are hierarchical (Grenfell, 2014). Bourdieu also made the assertion that the members of a certain class often strategise in order to maintain or improve their position in the field, as a field is a common site of struggle and dispute (LiPuma, 1993; Collyer, 2015). Additionally, Bourdieu identifies social agents' sense of 'feel for the game' that becomes second nature to them (Bourdieu, 1990). These may be the underlying reasons for the dominant role taken by some of the HCPs in making decisions regarding their T2DM patients' management.

Nonetheless, Bourdieu emphasises the contribution of social agents in prescribing their practices even when they are within the above-described hierarchical social field (Bourdieu, 1977). Bourdieu also believed that habitus and field are interrelated; for example, not only that the rules in the field can influence social agents' habitus, but also that the 'feel for the game' commonly evolves as a result of a change in the embodied experience of the social agents (Bourdieu, 1993).

Capital

It is often the case that the social position of the agents in the field is based on their possession of capital, which is something that will usually take a lot of time and effort to build, especially in the case of social and cultural capital. Capital has a direct association with power relations that will determine the practice of the agents together with their habitus and field. It is described by Bourdieu (1986: p. 46) as *"... a force inscribed in objective or subjective structure"* and *"... the principle underlying the immanent regularities of the social world"*. Bourdieu broadened the existing concept of capital at that point, which up to then had focused mainly on economic capital, by introducing social, cultural and symbolic capital. However, these resources will only become valuable if the society/group in the field value them collectively and they ultimately provide a significant advantage in the form of power and dominance to those individuals or groups who hold them (Bourdieu, 1998; Grenfell, 2014). Besides interacting with habitus within the field boundaries, it is common for the different types of capital to be interconnected and create significant

force or power dynamics that eventually shape the practice of the agents in the specific context.

Economic capital

Economic capital is the longest-standing source of power and domination. It refers to tangible assets, such as money and possession, and right up to the present, economic capital has served as a resource for the other types of capital (Bourdieu, 1977; Bourdieu, 1986). This is because the attainment of the agents' social, cultural and symbolic capital has been boosted by economic capital. For example, it is common for those who are rich to have better access to education, which is one of the main resources of cultural and social capital. Besides, in Malaysia, the rich will usually go to the private hospitals that provide them with access to a better healthcare service (Thomas, Beh, & Nordin, 2011).

Social capital

Bourdieu defined social capital as *"… the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance and recognition"* (Bourdieu, 1986: p. 51). Individuals with a bigger and stronger network occupy a better social position or hierarchy in the field. The understanding of social capital is extended to include the groups to which the individual belongs and the difference between these groups in terms of their status and power (Bourdieu, 1986; Putnam, Leonardi, & Nanetti, 1994; Szreter & Woolcock, 2004). Putnam (2000) further emphasised the importance of reciprocity and trust within and between different groups when it comes to them obtaining their needs. In the healthcare system, HCPs are considered to have a higher level of social capital compared to patients as they occupy a position of formal authority within the system and act as gatekeepers between patients and healthcare resources.

Cultural capital

According to Bourdieu (1986), cultural capital can be categorised into three distinct states: embodied state, institutionalised state and objectified state. Culture is considered to be the most prominent form of embodied cultural capital. For this type of cultural capital, the process of embodiment often does not occur instantaneously and happens unconsciously. The acquisition of cultural capital varies depending on the duration and the society in the field. In addition to culture, language, skills and education are also listed as cultural capital by Bourdieu. The institutionalised and objectified states are the ways in which others are informed of one's acquisition of cultural capital. These may be in the form of educational certification, writings, paintings and other material objects that serve to describe cultural capital.

In using the concept of cultural capital to understand patient–HCP interaction in the field of healthcare, cultural capital was further extended by Shim (2010) to become known as cultural health capital. It is defined as *"… the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviours and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships"* (Shim, 2010: p. 1). Shim's work on cultural health capital focuses on this type of capital possession among patients, covering their cognition (linguistic facility and ability to understand biomedical information), attitude (proactivity in accumulating knowledge) and behaviour (ability to use the biomedical information and instrumental approach to disease management). Shim also argues that her concept of cultural health capital is particularly helpful in understanding the social production of the unequal patient–HCP interactional dynamics between patients and HCPs.

Symbolic capital

Since power relations is one of the most prominent emerging issues in the data of this study, this category of capital is considered to be the most pertinent to this study. It is a type of capital that is formed through a legitimatisation of the other types of capital and is often understood as 'honour' or 'prestige' (Lawler, 2011). Bourdieu entered

into an extensive discussion of this type of capital, and it has its own section in his books *Outline of a Theory of Practice* and *The Logic of Practice*.

Bourdieu (1977: p. 76) described symbolic capital as *"... conventional and conditional – stimulations, which act only on condition they encounter agents conditioned to perceive them, tend to impose themselves unconditionally and necessarily when inculcation of the arbitrary abolished the arbitrariness of both the inculcation and the significations inculcated"*. Thus, the conversion of other types of capital to symbolic capital is deemed to be important as this is the most effective way for the individuals or groups with the capital to acquire an advantage or power within a specific context or field. Symbolic power is a more implicit form of capital, thus rendering it more acceptable in the social world. In this study, several symbolic capitals emerged as factors that have relations with the practice of shared decision-making. These include the patients' socio-economic status, illness experience and knowledge, the HCPs' health and medical expertise, and both groups' language and communication skills.

Symbolic power and doxa

In discussing practice, habitus and field, Bourdieu also routinely talks about symbolic power. Symbolic power depends heavily on the possession of symbolic capital (Bourdieu, 1989) and, similar to symbolic capital, is a legitimised form of another type of power. Symbolic power is inseparable from language due to the fact that language is used as a means of transforming other types of power into symbolic power. Symbolic power, however, is considered to no longer exist once the accumulated capitals which produced the power are no longer recognised or considered to be collectively useful. The HCPs are considered to be the group with more power in the healthcare system as they possess more capitals in comparison to the patients. However, in the current changing world, there are changing perceptions of the meaning of these capitals. More often than not, this leads patients to question their HCPs' decision, with the effect that the advice and prescriptions given by HCPs are no longer carried out or followed without hesitation.

As for *doxa*, this is a product of unquestioned symbolic power within the field among agents with similar habitus (Grenfell, 2014). There is a legitimation or recognition of *doxa* as something that should be accepted by all agents of the field as being both the 'rules of the game' and indisputable. The acceptance of *doxa* as a common belief is not due to any external force but rather results from the agents' internalisation of the forces, predisposition and/or experience which further shape the habitus and field (Grenfell, 2014).

Modes of domination

Power is commonly associated with actors in a higher position exerting dominance over those in a lower position. In his writing on 'Modes of Domination', Bourdieu states that *"... domination no longer needs to be exerted in a direct, personal way when it is entailed in possession of the means (economic or cultural capital) of appropriating the mechanisms of the field of reproduction by their very functioning, independently of any deliberate intervention by the agents"* (Bourdieu, 1977: pp. 183–184). It can be said that domination is not directly exerted through the possession of capital but that it usually occurs autonomously as the institution serves as an instrument to facilitate the reproduction of domination in the field. On the other hand, the ability of accumulated capitals to be objectified is also important in determining the modes of domination and ensures that the domination is reproduced (Bourdieu, 1977). This may serve to explain why those HCPs who prescribe or allow patients access to medication and wider healthcare services are always viewed as having more power and domination compared to HCPs who merely give advice to patients. In this study context, only medical officers, FMSs and endocrinologists have the authority to do so.

3.7.4.2 Integration of Bourdieu's work in data analysis

Although there is debate as to whether Bourdieu's work on habitus, capital (economic, cultural, social and symbolic), field (the arenas of social structures and struggles), doxa and power (including symbolic power, domination and symbolic

violence) can be considered outdated, it was nevertheless deemed to be the most comprehensive form of guidance available for use in making sense of the complexity of the gathered data. According to Collins (1993), Bourdieu's work is also relevant as it bridges the 'objective' social structure and 'subjective' human characteristics and practice, in addition to providing a means of understanding the power relations that exist among people in certain contexts and fields. These are aligned with both symbolic interaction, which is the theoretical underpinning, and qualitative research as the methodology of this study (Crotty, 1998; Patton, 2002). Furthermore, Bourdieu's social theory and the concept of power are a good fit with constructivism, which is the paradigm of this study, as they value the views and experiences of each social agent within the boundaries of a specific social field. Multiple perceptions and practices are anticipated as the field is heavily influenced by individual habitus and possession of capitals. Thus, his theoretical notions on the above-mentioned aspects were used extensively to guide further analysis and discussion in constructing a theoretical understanding and building intricate interrelationships or associations between the elements that emerged from the data, which are the main contributions of qualitative research (Patton, 2002).

Besides, taking his recognition that cultural order (cultural capital) and social structure are parallel, the work of Bourdieu can further explain how the actions of both patients and HCPs are not only the result of an internal practical logic and individual disposition but are also moulded by the social structure (field) in the healthcare system and the Malaysian or Asian cultural and social backgrounds from which they emerge (Bourdieu, 1977; Bourdieu, 1990). These are useful when extensively exploring the contextual factors that influence the practice of patient involvement in decision-making, which is unique to this study. Table 6 contains an example of how Bourdieu's work was adopted in facilitating the emergence of themes in Chapter 5. The result of this adoption in analysing the data of this study is presented in Chapter 5. This led to further utilisation of his work in Chapter 6, especially in 6.4, which contains discussion about the patient–HCP interpersonal relationship, and in 6.6, on the power relations in decision-making.

Table 6: An example of emergent themes from codes using Bourdieu's work

Transcripts	**Codes**	***Theme***
"What is the point for me to be clever? I don't have any expertise. You are the doctor, you tell me." (PT2, 61-year-old Indian man, SC)	**Patients' expertise and contribution (habitus and cultural capital)**	**Patients' characteristics, values and belief**
"When I was working, I got my medication from the private, I could ask for something more. RM1000-RM2000, they can give me, but when you come to the government hospital, they say, "look, I don't have any other thing, this is what is available, what I can give to you?" They give, I'll take. Our treatment method is not right. But if you are the type who doesn't have the capability to buy, go and see the government doctor, they'll give the best treatment. Because the treatment is good, but not the medication, government doctors do not have it. It's quite expensive. If you're not rich and just average, forget about it, government servant and all that. It is for the rich so, I'll just go on with it. The medications are there, but it's for the rich and famous." (PT17, 58-year-old Indian man, CC)	**Patients' acceptance of public facilities (habitus and field)**	
"I will wait and see. I'll see the changes, if it is needed for me to tell them, I will tell. If not, I will just stop…I have taken this nerve medication for so long, I can say that I've tried everything from A to Z, but no changes." (PT8, 61-year-old, Malay man, HC)	**Patients' belief and value in the treatment modalities (habitus)**	
"Maybe the patients become a little bit more passive, they do it for the doctor's sake. Maybe, they want to please their doctor. Some doctors are very strict, so they do it because they want to make sure when they come to the check-up everything is good, so the doctor will be happy." (HCP19, endocrinologist, HC)	**Being a good patient (habitus)**	

The accordance with symbolic interactionism is strengthened through this section's discussion on the adoption of Bourdieu's work as the analytical tool with which to explore the factors that influence the practice of patient involvement in decision-making in the study context. This is because it supports the three main premises of symbolic interactionism by Blumer (1969): (1) human beings act towards things on the basis of the meaning those things have for them; (2) the meaning of things is a social product; (3) meanings are handled in, and modified through, an interpretive process used by a person when dealing with the things they encounter.

3.8 Data Management

The data relating to the participants were stored in separate folders. Each folder contained all of the data obtained from each participant, including an audio recording of the interview and its original transcript, the English translated transcript (if any) and related notes. The data analysis for this study was also supported by the qualitative data analysis software package NVivo 10. This software helped me to systematically manage the rich and thick data obtained during the interview sessions in terms of storage, coding, retrieval and making comparisons and linkages, yet the analysis was still done by the researcher (Patton, 2002). NVivo was chosen over other available computer-assisted qualitative data analysis software (CADQAS) due to my familiarity with the software and the fact that it is both available at and supported by the university. Besides, this software also functions well with different qualitative designs and data analysis techniques, including thematic analysis (Zamawe, 2015).

All of the hard copies were stored in a locked cabinet, accessible only by me, while electronic copies were stored on my laptop and desktop with an access code. All of the documents, including the audio recordings, will be destroyed in accordance with the University of Edinburgh research protocols.

3.9 Ethical Consideration

3.9.1 Ethical approval, and access to sites and study participants

Ethical approval was sought from the School of Health in Social Sciences, University of Edinburgh Ethics Committees prior to the commencement of the study. At the same time, an online application was submitted to the Malaysia Research and Ethics Committee (MREC) and the Malaysia National Medical Research Registry (NMRR) to request ethical approval to conduct the study in the selected hospitals and health clinic. Approval was also sought from the Economic Planning Unit, Department of Prime Minister as the analysis of this study was conducted outside Malaysia.

The process of gaining access to the study sites only commenced once approval from all of the above-mentioned ethics committees and unit had been granted. This was done by sending an application letter to the State Health Director, District Health Officer, Hospital Director and the Clinical Research Centre of the hospital. Once all of the relevant parties had approved the study proposal, letters were sent to the gatekeepers at the study sites, which included the heads of department and nursing administrator at the hospital and the medical and nursing administrators at the health clinics, requesting access to the sites and study participants. Later, appointments were made with these gatekeepers so that the aims, objectives, purpose of the study and data collection activities could be thoroughly discussed. This process was very important for building rapport and securing the cooperation of the gatekeepers in order to assist the data collection process (Patton, 2002; Holloway & Wheeler, 2010). With their permission, a brief initial observation was carried out to gain further understanding of the process of T2DM management at each of the study sites.

Initially, four health facilities were approached; two health clinics and two medical/endocrine clinics located at two different hospitals. However, data collection was only carried out at three of these facilities. This was because of a newly created regulation put in place by a head of department at one of the initially selected hospital that required the involvement of one of their staff in a research project just

prior to the data collection. No further action was taken in respect of this site as the other selected hospital's specialist medical clinic had sufficient capacity to provide the required participants. Thus, data were collected from three health facilities: two health clinics and one hospital medical/endocrine clinic.

3.9.1 Informed consent and voluntary participants

There was no anticipated risk associated with this study. However, informed consent was obtained from each participant to ensure they were fully informed and willing to participate voluntarily in the study. In order to obtain written informed consent, the potential participants were thoroughly informed regarding the details of the study, their comprehension was checked and they were given the freedom to either participate or decline (Bryman, 2016). Their right to withdraw from the study at any time, even after they had consented, was also clearly explained in order to respect their rights as study participants. Additionally, the patients were given a guarantee that their decision to participate in this study would have no bearing on their treatment in the future.

A participant information sheet, available in both English and Malay (refer to Appendices 1 and 2), was provided to each potential participant to assist them in their decision to become involved in the study. They were given sufficient time to read the sheet, ask questions, address any concerns they may have had and consider whether or not they wished to participate. An informed consent form was then signed by each participant who wished to participate prior to the interview, thus indicating their understanding of the study and their agreement to participate. Finally, the participants' consent to be audio-recorded was established prior to the interview.

3.9.2 Anonymity and confidentiality

Guaranteeing the anonymity of the participants in a study is paramount (Grinyer, 2002), with the potential for a participant's identity to be uncovered being relatively high in a qualitative study (Holloway & Wheeler, 2010). All of the written interview

documents and information obtained about the participants, which also contained the written consent forms with their names on, were kept confidential and separate from the interview data.

Furthermore, the patients' names were removed from the transcripts and replaced with non-identifiable pseudonyms. Only I as the researcher am able to match the identity of the participants to their voice recording. Since two external transcribers were hired, an agreement was sought from both transcribers with respect to their nondisclosure and maintenance of confidentiality of the recordings, and the transcriptions and recordings were sent via password-protected email and disposed of immediately following completion of the transcriptions. All of the transcriptions were carried out in a private room using headphones/earphones so that the recordings were not heard by other people. Furthermore, the transcripts that were shared with the study's supervisors to confirm the accuracy of the analysis and interpretation were shared in a similar way to how the data were shared with the transcribers, namely via password-protected email.

The possibility of anonymised verbatim interview quotes being used in reports, publications or presentations was explained to the study participants, and their consent regarding these matters was sought. No details that had the potential to lead to the identification of the participants were included in the shared transcriptions or extracts/excerpts in this thesis. Any reports or publications that arise from this study will also include only anonymous excerpts.

3.10 Rigour of the Study

Rigour in qualitative research is described as 'trustworthiness' and relates to the quality of the data; it is also known as validity and reliability in quantitative research (Welsh, 2002 and Bryman, 2016). Trustworthiness in qualitative research is achieved when the researcher fulfils at least two of the eight strategies for validity and reliability as suggested by Creswell (2007). These comprise prolonged engagement

and persistent observation, triangulation, peer review, analysis of negative cases, researcher reflexivity, member checking, rich and thick description and external audits. In this study, more than two of these strategies were adopted to ensure its trustworthiness.

3.10.1 Prolonged engagement

Data were collected from the study sites during the period between November 2015 and April 2016. Despite in-depth interviews being the only method of data collection used, I spent the majority of this period at the study sites. The reason for this was not only to build relationships and trust with the staff in order to facilitate the participant recruitment process, but also to learn and understand the study sites' environment and culture so that contextual understanding of the participants' narrative and meanings could be achieved (Creswell, 2007; Lundy, 2008).

3.10.2 Triangulation

Triangulation in qualitative research is vital in establishing credibility and confirmability (Lincoln & Guba, 1985). It can be carried out by having multiple and different theoretical perspectives or theories, methodologies, methods of investigation and/or sources of data (Denzin, 1970; Fielding & Fielding, 1986). As the data were collected through interviews, triangulation was carried out within the method in order to attain greater accuracy and credibility of the findings (Denzin, 1978). This was done by having multiple viewpoints of the patients and HCPs from three different clinics, incorporating relatively different systems for managing T2DM. Besides, as mentioned in the recruitment of study participants section of 3.6.2, patients with different sociodemographic and T2DM characteristics, in addition to different groups of HCPs, were recruited for this study.

3.10.3 Peer review

The issue of peer review and debriefing was addressed in this study with the help of the two study supervisors. Frequent and extensive discussions on the research

protocols, methodologies, interview transcripts and the analysis process were held between both of the supervisors and me. Both supervisors acted as what Lincoln and Guba (1985) describe as 'devil's advocate', in that they prompted me to consider things or situations from different perspectives in order to reduce my implicit assumptions and bias, thereby increasing the study's credibility.

3.10.4 Rich and thick description

In this study, coupled with a thick description of the settings and context (including geographical and sociocultural characteristics), rich and long excerpts from the participants were also included in order to provide the reader with a detailed description of each finding that would enable them to make a judgement with regard to their transferability (Geertz, 1973b; Lincoln & Guba, 1985). According to Lincoln and Guba (1985), rich and thick description is important in helping readers to determine the potential for transferability of the findings of this research to other settings or contexts.

3.10.5 Researcher reflexivity

Researcher reflexivity is a description of the researcher's background and experience, which is an indispensable element of qualitative research. This act of self-reflection serves to provide clarification on how the researcher's past experience, biases and personal judgement may influence the way in which the study was conducted from the initial phase of planning right up to the end when the findings were analysed and presented (Creswell, 2007). Researcher reflexivity is described more fully in 3.11. This explanation is important not only to advise the reader on the researcher's position but also to minimise biases as I was aware of how these factors had the potential to affect my study. Its inclusion therefore ultimately increases the credibility and confirmability of the study (Lincoln & Guba, 1985; Finlay, 2002).

3.11 Reflexivity

The issues of bias and qualitative research are inseparable as the researcher acts as an instrument for both the data collection and analysis. The fundamental recommendation is for the social researcher to keep their distance so that they can maintain their objectivity throughout the research process. However, according to Patton (2002: p. 49), in gaining a full grasp of the data, especially when it comes to meaning-making that is associated with participants' cognition and emotion, *"… understanding comes from trying to put oneself in the other person's shoes, from trying to discern how others think, act and feel"*. This shows that there is a need for researchers to put themselves in the participants' position so that they can understand their opinions, emotions and behaviour, empathetically.

However, it is also important for researchers to be transparent and present the detail of the study process so that bias can be reduced. This is known as reflexivity and it helps the researcher to be aware of their own interpretation of the data at the same time as informing the reader of the researcher's background knowledge, values and beliefs that may impact upon the research (Finlay, 2002; Charmaz, 2006). In line with the paradigm and theoretical perspective of this study, which are constructivism and symbolic interactionism, the researcher's contribution to a research process is significant as their experiences, cognitive predisposition and emotions help them in understanding the phenomena or social reality in question. Thus, discussion on the researcher's reflexive stance is crucial as it is strongly linked to the quality and credibility of a qualitative study.

As described earlier in section 3.6.3.4, notes were written and kept immediately after each interview. Despite the fact that these notes were not analysed, they served as a reflexive tool as they included my personal thoughts and feelings throughout the interview sessions. Besides, as the notes detailed the non-verbal communication cues such as body gestures and facial expressions that could not be captured by the audio recorder, they provided some profound context to the participants' answers and the gathered data. Working in this way helps to reduce the potential for misinterpretation

of the narrative, thus hopefully ensuring the trustworthiness of the study (Bryman, 2016).

Despite the intention to comprehensively explore patient involvement in health decision-making and shared decision-making, I admit that my background of having a Master's in Health Education led to me having a greater interest in the information sharing and communication between the patients and their HCPs. This was further strengthened during the review of the literature, where both of these elements are listed as prerequisites for shared decision-making (Charles et al., 1997; Coulter, 1997; Elwyn et al., 2000; Makoul & Clayman, 2006). However, throughout the planning of the study, including setting out the research aims and questions, data collection and data analysis, no significant focus was given to this element. The exploration was also carried out based on an integrated model of shared decision-making by Makoul and Clayman (2006). This is a comprehensive model that integrates the extensive existing literature on the shared decision-making model. Aside from the shared decision-making model, I chose not to use any other theory in the initial stage of my study so that no premature focus could be accorded to any specific realm. However, my interest in the communication and information exchange elements was again reinforced as they emerged significantly from my data, thus leading me to gravitate further towards those elements.

However, as I shared the interview transcripts and my analysis with both of my supervisors, my interpretations and analysis were constantly challenged, especially during the first half of the study process. On the other hand, the constant comparative method also helped me to remain objective with my data, as I constantly had to compare the data not only to find differences and similarities but also to make sense of incidents or the occurrences based on the participants' narratives. This is because, despite being one of the important elements listed in the existing shared decision-making models, the underlying factor of power relations became the main reason for the current practice to revolve around patients' involvement in decision-making in the study context.

Nonetheless, the benefits of my previous background and a further exploration of the information exchange led me to identify power relations as the main underlying theme that greatly influenced the extent of patient involvement in the decision-making process. This further guided me to use Bourdieu's theory of practice and his work on power relations, both of which facilitated further exploration and explanation of the properties of the emerging categories and ultimately provided a framework for me as the researcher to produce a more relevant and concrete connection between the categories or themes, compared to using my implicit assumptions and interpretations as a base. According to Hertz (1997), this is how a reflexive researcher should contribute to her/his study and not merely become a reporter of the participants' narratives; as such, she/he should actively continue to construct and question her/his interpretation of the collected data.

Constructivism greatly relates not only to the meanings that participants attach to their experiences and their perceptions of social reality, but also to the construction of understanding and interpretation of these meanings and perceptions, which is predominantly conducted by the qualitative researcher. This, coupled with the task of the researcher, as the interviewer, to gather the information from the patients meant that the power dynamic between the participants and myself was taken into account during the study's data collection. Power asymmetry is common in research interviews as the researchers hold the power in terms of scientific competency and they also have the power to shape the setting of the interview sessions (Brinkman & Kvale, 2015). Consequently, some participants may react undesirably as counter control measures. These may include a refusal to share the truth, changing the subject, questioning the intention of the researcher with regard to the asking of certain questions and, in the worst-case scenario, withdrawing their participation (Brinkman & Kvale, 2015). Power asymmetry in the research interview is not something that can be eliminated; however, by acknowledging and being aware of its presence, the hope is that it can be reduced so that any impact will be less severe or else can be avoided completely.

All of the patients were informed of my position as a doctoral research student and that I had no affiliation with the study sites or the MOH. It was important that the participants did not feel threatened by me, which was again emphasised in the cases where I sensed that the participants were trying to conceal the truth or their real opinions or feelings. This also reaffirmed the need for their anonymity. Throughout the duration of the data collection, my background as a nurse became identifiable to some of my participants. Realising that this may distort their perception of me and result in them taking counter control measures, I reassured them by emphasising that my current role was that of a researcher and not of a nurse in clinical practice. Despite this, however, it could be sensed that some of the participants were trying to give a positive impression when answering the questions.

Additionally, when entering the study sites, it was common for me to meet patients, as my participants, who did not understand about and/or adhere to their T2DM management. As a nurse, it was disheartening for me to discover this, but I was unable to consult or advise them further since my role at the time was as a researcher. Instead, I could only tell them to discuss their concerns and issues with their HCPs at the very earliest opportunity. Finally, my previous experience as a nurse who used to care for patients with T2DM served as both a friend and foe throughout. Being a novice qualitative researcher, it was hard for me to look at the data solely through a researcher's lens and put aside my nurse's lens. As such, in some instances, I tended to make premature conclusions with regard to the issues emerging from the data. This is where my supervisors again played a role.

3.12 Limitations

Even though diversity among participants was kept in mind during the collection of data for this study, due to its purposive sampling and the small number of participants, who were concentrated in an urban area, the findings of this study cannot be generalised to the wider Malaysian population. However, similar to most qualitative studies, this was not the main aim of this study. Conversely, this study was mainly conducted with a view to building a theoretical understanding of the

meanings and views that the study participants ascribed to their social reality and the world.

However, as the study employed only in-depth interview as its data collection method, there are two major concerns regarding the data of this study. One of the major issues concerns the veracity of the data that were given by the participants. As mentioned earlier in section 3.10, there were some participants who tried to conceal their true feelings or behaviour and practices, or the real occurrences, and presented me with only the nice parts. This was especially true when it came to activities that could potentially leave me with a negative impression, such as non-adherence, dissatisfaction with the services received, limiting patients' opportunity to be involved in the discussion and others. However, as the interview progressed, and the more the participants felt comfortable and the more questions were asked, the more the realities and truths were revealed.

Another disadvantage of the interview in this study was that there was a high probability of some details not being shared or otherwise excluded by the participants, and not because they wished to hide them from me (Bryman, 2016). Such an occurrence may instead have been because the participants had to retrospectively recall various events, including distressing ones, and this could be very demanding for the participants involved, especially the patients. Some patients also had difficulties in answering some of the questions due to their poor or repressed memories. In some cases, the participants may not have shared the important details as they did not consider the matters to be worth mentioning. Several measures were taken to address these issues.

Furthermore, some of the patients in this study were identified with the help of HCPs. This may introduce ethical issues to the study recruitment. This potential for bias could be due to the patients' perception regarding the impact of their participation in the study on their relationship with their HCPs, or their concern about the treatment they would receive from the HCPs, and the HCPs' protection of vulnerable patients

(Mason et al., 2007; Wilson, Draper & Ives, 2008). However, this concerned only a small number of the patients in this study and the recruitment was not carried out directly by the HCPs. Instead, the HCPs directed me to the patients that they considered suitable for the study, and I then approached and recruited them. This was believed to negate any feeling of obligation to participate on the part of the patients.

As I can only understand and converse in English and Malay, the data were only collected from people who could also understand and converse in these two languages. As a result, only a small number of Indian and Chinese patients were successfully recruited in this study. Although Malay is Malaysia's national language, not many Chinese and Indian people, especially the elderly, are able to converse in either Malay or English, the latter of which is considered as the second language. Hence, the issue of a language barrier, which was mentioned by the HCPs, could not be explored from the perspective of the patients as it was never raised by any of those whom I interviewed, and I did not have access to the same patients with whom the HCPs had language problems.

3.1 Chapter summary

This chapter began by outlining the methodological issues and research design of this study. As presented, the main aim of this study is to explore the understanding and perceptions of patients and HCPs of patient involvement in decision-making and also shared decision-making in the management of T2DM in Malaysia. The justifications of constructivism and symbolic interactionism as the theoretical philosophy underpinning this study were thoroughly discussed. This then led to the identification of an interpretive qualitative research method as the most suitable approach for conducting this study.

Relying on the chosen research paradigm, the methods used to conduct the study were presented in detail, including the sites of the study and the sampling strategy for both the patients and HCPs. The in-depth interview was found to be the best method

to use to answer the research questions as it allowed me to gain an extensive understanding of the meanings that the participants ascribed to their experience of the involvement of patients in decision-making and their perception of shared decision-making. The data in this study were analysed using thematic analysis with the support of the constant comparative method in order to uphold the emic (participants' narratives) and etic (researcher's interpretation, theoretical framework) perspectives in this study (Fram, 2013). This chapter also contains an explanation of Bourdieu's work on practice and power relations as this was used as the theoretical framework to further analyse and discuss the emerging issues that were identified in the middle of the data analysis.

Furthermore, the ethical considerations of the study were also outlined in this chapter, including ethical approval and access to the sites, informed consent and voluntary participation, and anonymity and confidentiality. As the rigour of qualitative study is also important, I explained the measures that were taken to ensure the trustworthiness or the reliability and validity of this study. Lastly, there was a discussion to present some of my reflexivity throughout the study process. This is to both inform the reader and to make myself aware of my reflexive stance in relation to conducting the study and also generating the following Findings and Discussion chapters.

CHAPTER 4: PATIENT INVOLVEMENT IN DECISION-MAKING

4.1 Introduction

This chapter explores the perceptions of patients and HCPs of the current nature of patient involvement in the decision-making process in the management of diabetic patients. Decision-making is one of the main activities in the patient–HCP encounter (Elwyn et al., 2001). Patient involvement in the process is currently an area of focus within the healthcare landscape, with an emphasis being placed on the shift from disease-centred to patient-centred care. The following sections detail the findings relating to an exploration of the perceptions of patients and HCPs regarding their experience of patient involvement in the selection of treatment and management for patients with T2DM. In this chapter the emerging findings looking at how these different groups of individuals perceive patient involvement in decision-making are organised based on the essential elements of shared decision-making presented in the previous Literature Review chapter. These elements are (1) identification of patient needs; (2) information sharing and HCPs' recommendation; (3) discussion and deliberation; and (4) final decision.

As this study involves patients and different groups of HCPs from different study settings, some additional information is included for each excerpt from the participants. Each excerpt from the patients is followed by their pseudonyms and the setting from which they were recruited. For HCPs, additional information about their job is also included. To enable differentiation of the accounts from patients and HCPs, different colours are used for each group, with blue for patient excerpts and purple for those from the HCPs.

4.2 Identification of patient needs

Based on the review by Makoul and Clayman (2006) on shared decision-making, defining patients' needs is one of the essential elements shared by the existing models. Indeed, analysis of the data from both patients and HCPs highlights the

emerging issues related to the way patients' needs are identified with respect to a new decision. These important issues include a cursory assessment by HCPs focusing on clinical parameters, patients' dependence on the HCP, patients' sharing of their practice, concerns and problems, meeting different individuals, and the language barrier.

4.2.1 Cursory assessment by HCPs focusing on clinical parameters

Most of the HCPs emphasised the importance of assessments for identifying patients' problems and needs, and these were usually conducted at the start of the session. The results were then used to guide the later stages of their encounters with patients.

> *… they come, and I will check, so while checking the leg, we will be asking questions, such as whether there is numbness or not. Do you feel any pain, is there any redness? And when they walk, is it normal or not? All these questions will be asked first. We will check BP and dextrostix. Based on the result, we will talk about the medication, if they are taking insulin or Dionil; whatever medication they are taking we will also ask about that. And then while checking the leg, we'll look for oedematous, pulse, lateral pulse, all the things we have to check. Then the nails, looking for any infection, some have no nails. And then we will look in between the toes, checking for any infection, itchiness or anything. And then plantar there, we will check for corn, callus and heel cracking and then the leg, whether there is any hair loss or not, we will enquire about that. Any pigmentation, colour change, any ulcer. (HCP1, staff nurse, SC)*

> *…we will assess their control in terms of, specifically, like hypoglycaemia, blood glucose monitoring, if they are doing it at home and then any issues with their diet, physical activities, and then usually have a quick examination. Depending on whether it's a brief or a more complete examination, we will mainly have a quick look at their feet. The other things that they may have had done include a foot examination before, by the nurse, or an eye examination at the eye doctor's. Then, lastly, we look at their blood lab results, focusing on their HbA1c, lipids, kidney function and then we wrap it all up to assess the current status of their diabetes control, their current status of diabetes complications…. (HCP19, endocrinologist, HC)*

The above excerpts by HCP1 and HCP19 indicate that assessment is carried out based on the HCPs' role in managing patients with diabetes. HCP19, who is a specialist and is mostly responsible for the overall management of patients with complex diabetes problem, conducts assessments that are more inclusive yet superficial in comparison to those conducted by HCP1, who is a nurse responsible for managing diabetic foot problems. This shows that a team-care approach to managing patients is very beneficial as a means of ensuring that patients are managed comprehensively and to reduce the risk of any clinical or physical problems being missed, despite the added redundancy. This is because not all patients have the opportunity to meet HCPs other than their own physicians in relation to the management of their T2DM. Nonetheless, both of the above accounts reflect how the main focus of assessment is on the patients' biomedical parameters, especially their glycaemic level and any diabetes-related physical changes. This is aligned with the main clinical indicator for the effectiveness of T2DM management issued by the MOH Malaysia within the CPGs (MEMS, 2016) and the traditional healthcare paradigm that focuses on the illness.

However, the IDF 2012 Clinical Guidelines Task Force (2012) also recognises patients' psychosocial status together with their knowledge and beliefs regarding their T2DM as the important elements to be assessed when managing patients with diabetes as these can negatively affecting their well-being (Grigsby et al., 2002; Nouwen et al., 2010) and may become a barrier to their diabetes management (Glasgow, Toobert, & Gillette, 2001; Fisher et al., 2010). There seems to be limited mention in the collected data of patients' psychosocial status, including their emotional burdens, concerns about diabetes, need for support and their thoughts on their disease condition and management, as an element that many HCPs will intentionally assess at any point in time. Analysis of the overall data has also revealed the limited indication of any tool for use in directly assessing patients' psychosocial and emotional status, which may be due to its recent development and introduction in Malaysia (Chew et al., 2015; Y.W. Chin, Siew, & Chia, 2017). However, it was commonly found throughout the data that the patients associate these non-clinical problems with their T2DM status.

> *It just goes up. It fluctuates. Sometimes, when you are okay, then the sugar is okay. Sometimes, when you feel stressed, it goes up. Because as far as I can see, my food intake is not that much. (PT13, 48-year-old, Indian woman, HC)*

PT13, for example, felt that her uncontrolled diabetes may be caused by stress, although this had not been properly addressed since no assessment had been conducted in this area by any of the HCPs she met, and neither did she share her thoughts with them. This concern is in contrast to the following account from HCP12, who did not consider stress to be a factor that contributes directly to an increase in a patient's glycaemic level.

> *Oh, yes, sometimes. They do come, they do tell other things other than diabetes. They are stressed because of this, sometimes their BP is high because of stress, or some other problem. Those kinds of things, they come out, we try to ... you know, do the DAS screening or things like that. So, we try to help them in that way, refer them to a counsellor. We do that. (HCP12, medical officer, CC)*

In the above excerpt, HCP12 admits that some patients do complain of suffering from stress and that this is further addressed accordingly. However, the excerpt also demonstrates that this medical officer considers stress to be mainly linked to patients' high blood pressure rather than diabetes, which could lead to stress levels among diabetic patients being overlooked. Despite the fact that a direct link between stress and glycaemic level remains controversial, Lloyd, Smith and Weinger (2005) argued that stress has a bidirectional association with patients' T2DM self-management and might negatively affect their overall well-being.

In the area of patients' knowledge, values and belief regarding their T2DM status and management, an assessment was mainly carried out by those HCPs responsible for delivering health education and counselling to patients, comprising mainly diabetes educators, pharmacists and dietitians or nutritionists. Yet, based on the analysis, physicians tend to grant access to such HCPs only to newly diagnosed

patients, patients with an uncontrolled glycaemic level or to those who have expressly requested to meet them.

> *Normally in the first session we'll do a pre-test, patients will answer about their medication, everything that they know. So at least I know what they know. So I don't have to explain more on that and focus on the parts which they don't know. (HCP3, pharmacist, SC)*

Based on the above excerpt by HCP3, patients' level of knowledge, especially in regard to their pharmacological modalities, was extensively assessed by the pharmacist to identify their main needs in facilitating T2DM self-management. In doing so, T2DM patient education with regard to their medication therapy with a pharmacist in Malaysia is guided by the DMTAC protocol so that an improvement in patient care in terms of quality, safety and cost-effectiveness can be ensured (MOH Malaysia, 2014). However, only a limited number of patients are involved in a DMTAC programme and it tends to focus on patients who are struggling to maintain their glycaemic level due to non-adherence to their medication (MOH Malaysia, 2010b).

> *For the patients who referred by the doctor, usually the doctors have set target and why did they refer the patients to us. They'll mention the reason that they refer patients, whether it's just for injection technique only or SMBG only. (HCP8, diabetes nurse educator, HC)*

In other cases, with HCP8 as an example, the main focus in the education session is based on a target set by the physician. This may be useful, especially when the HCPs have limited time with patients, yet it may also be detrimental as it may limit the opportunity to explore other underlying issues, as demonstrated by HCP16 in the excerpt below.

> *As we already thought that they're not compliant and take care of themselves. That's why we just say to them, 'Okay, you have to follow, ABC, and if you're not your sugar will be high.' But, actually we don't know how they take the*

medication. Are they really taking their medication? Do they know about hypo? About diet? Maybe, they've never had a consultation with a dietitian …We've given the medication and if they take it the sugar will decrease. But we don't know that our patients actually go for traditional and all. (HC16, dietitian, HC)

HCP16 also highlighted that any assumption made by HCPs concerning patients' non-compliance may further heighten the possibility of missing the main concern of the patients, as previously mentioned by PT3.

4.2.2 Interaction during assessment

Similar to the following account by HCP19, most of the HCPs admitted that they asked their patients questions with regard to gathering the necessary information, in contrast to working based solely on the test results and findings from the physical assessment. This serves as a positive indication that HCPs are acknowledging the importance of patients' contribution during their clinical encounters. Asking patients is one way of gathering the information needed to identify their health problems and needs, in addition to it facilitating interaction between both parties.

…and during that time usually what we'll do is ask them if they have had any other problem between their visits that they want to discuss, usually medically related. (HCP19, endocrinologist, HC)

Different people have different problems. Not every patient has the same problem. (PT13, 48-year-old, Indian woman, HC)

Two-way interaction during the assessment was also seen as vital among the patients, as illustrated in the above account from PT13. This patient wishes to be understood by her HCPs as an individual who suffers from T2DM, and not merely as another diabetic patient, with the latter type of approach potentially leading to generalised management based on standard guidelines. This corresponds with the patient-centred care approach in which the patient should be treated both as an individual and

holistically, with their care decisions based on their background, preferences and values (IOM, 2001; Royal College of General Practitioner, 2014). Besides, in comparison to the identification of acute health problems, which is more straightforward, the identification of problems faced by patients with diabetes and their needs is more complex as it can be influenced by many factors and involve multiple modalities, which may require customised management (Murrow & Ogiesby, 1996). Despite having the same uncontrolled glycaemic level, the reasons for this are not necessarily the same for every patient and may not necessarily require any modification to their pharmacological modalities. In terms of this study, this may be more apparent in HC as it receives more complex cases due to its status as a referral centre for diabetes in Malaysia.

However, similar to findings by Witry and Doucette (2015), the HCPs in this study were more likely to pose additional questions to patients they considered to be problematic relative to those who they assumed did not have a problem. The determination of whether or not a patient was problematic was again made based on their glycaemic level, as illustrated in the following excerpt from HCP5.

> *Usually I will ask, when I can see that the sugar is out of control and I have to trouble shoot, I have to ask, I have to find out why, is it because of the injection technique or so on and so forth. (HCP5, medical officer, SC)*

> *She didn't ask anything, she just asked how I was. As for my diabetes, she just glanced through, as my sugar level is under 10. That was it. She didn't ask anything else apart from that. (PT1, 82-year-old Malay man, SC)*

This lack of assessment by HCPs of patients with no apparent clinical and/or physical problem is supported by the above statement by PT1. The account indicates that the HCP enters into no further discussion, particularly if there is no significant abnormality in their clinical parameters or physical characteristics. This may have the effect of delaying the early identification and prevention of problems among patients who have no apparent issues or problems. Furthermore, since referrals to

other HCPs generally depend on medical officers (as mentioned earlier), this may further hinder the proper identification and addressing of patients' underlying non-clinical or non-physical issues.

> *Okay usually all their investigation will be attached. So we have FBS, RFT, LFT and then HBA1C. So we will go with all the results, and then we'll have a look at it first, how's the reading for now. And then we'll look at their compliance. Basically, because we have a very short time only. There are a lot of patients, so not much time to spend, but whatever time is there we utilise. So we'll see the compliance, we're worried at that time, are they experiencing any reaction? Are they able to tolerate the medication? Are they compliant? And then next one, first medication and after that their lifestyle. What are the lifestyle changes that they've done to cope with diabetes? And then we encourage them to join our programme as well… You know you can't talk much. Counselling will take time, so it depends. I might do it. I have to address today's problem and give the appointment. (HCP12, medical officer, CC)*

Nevertheless, HCP12, in the above account, voices her concern about not having enough time to go beyond what she thinks is important in managing patients with T2DM. This concern is also shared by many other HCPs, especially among the medical officers. In relation to the finding by Seale, Anderson, and Kinnersley (2005), in comparison with non-physician HCPs, the physicians in this study are all likely to have limited time to spend with each patient as a result of their heavy workload. This time constraint hinders them from conducting a thorough question and answer session with the patient, which is aligned with the assertion by Loh, Yip, Packer, and Quek (2005) that some Malaysian HCPs have a time-conscious attitude. This is more apparent among medical officers, who normally have only around five to ten minutes to spend per patient, thus arguably compelling them to focus on patients' glycaemic levels, verbally expressed complaints and whether or not any clinical examinations have been undertaken. On the other hand, although some patients may have more detailed assessments when meeting with other HCPs, the findings discussed in this subsection demonstrate that most of the HCPs concentrate on managing problems that are clearly manifested both clinically and physically. This is again aligned with the biomedical model and tends to disregard patients'

emotional, spiritual, social, cognitive and psychological challenges (Arnold, Butler, Anderson, Funnell & Feste, 1995).

4.2.3 Patients' sharing of their practice, concerns and problems

Diagnosing patients' problems is the first step in the decision-making process for which the HCPs are accountable. Nevertheless, patients also play an important role in sharing their concerns and needs during their encounters with HCPs (Towle & Godolphin, 1999). In addition to the fact that most diabetic patients did not come to the clinic with acute health problems, based on the findings in 4.2.1, there were a number of occasions where the patients' main needs related to their psychosocial problems were not correctly identified as a result of the lack of comprehensive assessment and sharing from the patients' side. However, some of the patients in this study shared their needs and problems with their HCPs, as illustrated below:

> *I stopped, then called and asked the doctor to change my medication. I don't wait until the next appointment as it is still a long way off. Then, the doctor just changed the medication. (PT22, 34-year-old Malay woman, HC)*

> *Previously, I was injecting, right. Then I stopped injecting. I told the doctor that I didn't have enough money to buy needles. The doctor said, "Okay aunty, I'll give you oral medication first". (PT20, 54-year-old Malay woman, CC)*

PT22 and PT20 are examples of patients who took the initiative to resolve their issues and problems without being asked repeatedly by their HCPs. Both PT22 and PT20 informed their physician that they had stopped taking their medication. PT22 was experiencing side effects, while PT20 had a financial constraint and was unable to buy needles for her injections. Despite their different reasons for doing so, both of these patients had discontinued their medication as they were under the impression that they needed a new prescription from the physician for their T2DM to be controlled. Most of the patients shared the same view, stating that they would share any problems that might lead to them ceasing to take their medication, which may

indicate their belief in the contribution of pharmacological modalities to managing their T2DM and the need for it to be properly managed. However, patients were likely to have a greater tendency to share problems related to their pharmacological modalities relative to those for other forms of T2DM management, since the former is heavily based on a prescription by the physician. This corresponds with the assertion by Leventhal, Phillips and Burns (2016) that the patient will play an active role as an act of coping when they perceive they are facing problems that require further intervention from the HCP. These accounts also demonstrate that these patients' autonomous actions in expressing their needs and problems facilitate shared decision-making and benefit both the patient and HCP. However, there were also other reasons that influenced the patients' decisions to share their concerns and present enquiries to the HCPs, as explained further in both this chapter and Chapter 5.

The below account by HCP6 illustrates how the HCPs appreciated patients' initiative in sharing their concerns and problems, without being prompted, as it eased the process of identifying the problems that needed to be addressed.

> *They did share their problems with us. So from there, we'll know how we can help them. (HCP6, diabetes nurse educator, HC)*

However, analysis shows that most of the patients were still fully reliant on their HCP to initiate and conduct the assessment. The following account by PT2 clearly reflects this patient's dependence on his HCPs to initiate the interaction between them so that his real problems could be identified and discussed. This reflects his belief that it is the HCPs' responsibility and he is convinced and trusts that they have the greater knowledge and skill to be able to do this.

> *Definitely they would know what questions to ask. We don't know… Similarly, as the doctors, they should know what questions to ask. In this situation, this is the problem, how to analyse it, they should know and I trust their judgement. (PT2, 61-year-old Indian man, SC)*

It never crosses my mind. I don't know why. (PT6, 54-year-old Malay woman, SC)

In contrast, it never occurs to PT6 to talk to any of her HCPs about her struggle to control her diet. This may be due to her inability to identify it as a problem that can and should be discussed with them. It is also sensed that neither patient was aware of the importance of their contribution in facilitating an accurate identification of the problems that needed to be managed because, despite their uncontrolled glycaemic level, neither patient had developed any other health problems. They might therefore have felt comfortable with the way their T2DM was being managed by their HCPs. In addition, Bugge, Entwistle and Watt (2006) found that patients will not share any information they do not consider relevant and appropriate to the HCPs concerned. However, these findings also parallel with one of the unique aspects of patient involvement in mitigating diagnostic errors as listed by K.M. McDonald, Bryce, Graber and McDonald (2013). They highlighted that patients will not usually be able to recognise or locate information that needs to be shared with their HCPs due to a lack of understanding of the diagnostic process, despite the fact that they are the ones experiencing the symptoms. In addition, the accounts by both PT2 and PT6 may indicate a lower level of health literacy and a sense of disempowerment (which is explained in the next chapter) as the patients failed to identify and share their problem. This is even more common among patients in Malaysia as they tend to be quiet and non-assertive during encounters with their HCPs (Kennedy & Mansor, 2000).

There are patients who just come and see us, but they don't do anything. Every time they come to us, they don't want to be involved at all. They totally depend on us to help them. So, I think it's hard for me to handle such patient. (HCP7, diabetes nurse educator, HC)

That would be detrimental to the patients because if they are not voicing their problems, or they are not telling the side effects of something which they are not agreeable with, it might not help them in the disease or their treatment process. (HCP17, medical officer, HC)

For HCPs, they are aware of their patients' full reliance on them, and it is not something that they appreciate, as shown in the accounts above. HCP7 assumed that patients become dependent on HCPs as they are not interested in being involved themselves. This assumption may be true, but several studies have suggested that patients' dependency on their HCPs may be incorrectly interpreted as it was found that the patients did not share information as they had not been asked directly by the HCP and due to the fact that they worried about the HCPs labelling them as difficult and considering them to be non-compliant (K. M. Mcdonald et al., 2013; Snow, Humphrey, & Sandall, 2013). Patients' concern with regard to the label given to them by their HCPs is further discussed in 5.2.4 in the next chapter. Whatever the reason behind the lack of problem sharing on the part of patients, most of the HCPs shared the same concern as HCP7 and HCP17 in terms of believing that this non-disclosure of important information by the patient may lead to difficulties in determining the direction of the discussion during the clinical encounter.

> *Once I told them I'm having an erection problem, but it's not my priority and they said it's okay… I'm coming to 58, it's not really an issue but as a human being, you have the ego, as it is related to my manhood. (PT17, 58-year-old, Indian man, CC)*

Meanwhile, in some other cases, with PT17 as an example, patients' concerns and complaints were not given proper attention by the HCPs, thereby hindering the patients from further sharing their concerns. According to Hajos and colleagues (2011), HCPs' lack of attention may be due to their tendency to underestimate patients' perceived concerns. The situation faced by PT17 is also comparable to a finding by De Berardis and colleagues (2002), who suggested that sexual dysfunction goes undetected in more than half of patients due to their HCP's lack of attention and investigation. Şahin and Şahin (2015) also posited that, despite the fact that sexual dysfunction (which affects both male and female T2DM patients), like many other T2DM complications, poses no risk of becoming a life-threatening condition, it may nonetheless have an impact on a patient's overall quality of life. Issues related to sexuality can be considered taboo in Malaysia, with discussion about it still entered

into with a degree of apprehension by both patients and HCPs, especially when the patient and HCP are of different genders (W. Y. Low, Wong, Zulkifli, & Tan, 2002; C. C. Ho et al., 2011). Thus, given that these types of problems are unlikely to show up in any biomedical test or regular physical assessment, the patients' ability to express their side of the story is important when it comes to making improvements to their quality of life. This will help HCPs make an accurate diagnosis, which will further aid them in identifying suitable treatment options to offer to the patients (Martin, Williams, Haskard, & DiMatteo, 2005). However, HCPs' lack of attention with respect to patients' sharing may serve to reduce their interest in remaining active in discussing the problem that needs to be tackled as they feel disappointed, inferior, unheard and uncomfortable with the HCPs' feedback (Entwistle et al., 2008). A similar assertion was also made by PT22, as given below:

> *...I've told him that I'm in pain, "The injection is painful, doctor". "It is painful, but there's nothing that we can do," he said, just like that. I've shared with him, "doctor, I do inject but I feel pain every time I inject". And he said that, I was quite shocked. (PT22, 34-year-old Malay women, HC)*

> *Maybe because she met a lot of patients who can't hear her very well, so she talked loudly. I'm a softly spoken person, and then she talked loudly, "what's wrong with this doctor, I'm sick here". "Your sugar is high!" It's not, I just entered the room and she already said it was high. Maybe it's just her feeling. I just keep quiet and follow. I just smile. (PT10, 35-year-old Malay man, HC)*

PT10 at times felt he was being 'ambushed' and not given the chance to communicate at all. This is more apparent during consultation with physicians as they tend to focus predominantly on patients' biomedical characteristics, often displaying reduced sensitivity regarding the concerns that their patients bring to the table (S. Collins, 2005). Thus, it is undeniable that such perception of the patients and conduct on the part of the HCPs may result in their patients feeling inferior, unhappy, unheard and uncomfortable, which further reduces their intention of becoming actively involved in the encounter.

Nonetheless, besides the time constraint that limits the HCPs' focus on patients' biomedical status, as discussed in 4.2.2, HCPs also have their own justification for the ways in which they respond to patients' complaints.

> *The doctor will change the medication or start insulin on top of their current oral medication. The patient will say, despite the fact that they have had their oral medication for years, suddenly that day when we added the insulin, they said that their appetite increased, or they had stomach ache, even though we know that those are not side effects of insulin. That's why we'll be like, "eh, it seems to be impossible that you immediately had stomach ache right after insulin injection. Why aunty?" "I don't know, after I injected and when I pulled, I definitely feel pain." "Is it stomach ache or pain at the injection site?" We have to ask further. (HCP13, diabetes nurse educator, CC)*

In the above account, HCP13 expressed her concern at the possibility of patients not being truthful when sharing their problems or in having their own agenda, as they only shared information after there had been an intensification of their management, which she viewed as a patient's way of rejecting it in a subtle way; this was previously identified by Joshi and Aravind (2017) as a common practice in Asian culture. This also reflects the HCPs' lack of trust in patients, which may be due to their past experience of dealing with similar situations in which patients attempt to present an excuse for rejecting the prescribed management. However, there is a possibility that the patients may not share their struggles and concerns in the first place as they perceive them as being minor and manageable and therefore not worth discussing with their HCPs (further explanation of this is given in the next chapter), or for some of the other reasons discussed in this section. It was found that any lack of concern for patients' health complaints on the part of HCPs that arises for these reasons can be a form of paternalism, especially when there is no further investigation of the matter and HCPs' inability to properly address patients' reported concerns results in the inadequate assessment and collection of patient data due to the focus being on the patients' biomedical status (Marvel et al., 1999; Beauchamp & Childress, 2013).

4.2.4 Meeting different individuals

Another important issue that emerged in describing the current practice of identifying patients' problem is the fact that most of the patients meet different HCPs during their follow-up and the HCPs, especially the medical officers, did not manage the same set of patients.

> *So when you have different doctors seeing one patient, these different doctors tend to, actually, maybe want to hurry up and they don't know the background of the patients so they only focus on the problem at that current time that they see the patients… (HCP19, endocrinologist, HC)*

HCP19 is an endocrinologist who meets the same set of patients. She realised, however, that most medical officers did not have the same opportunity to review the same patients, similarly for the diabetes educators at HC who work on a rotation basis. In the excerpt above, she mentioned that this would most probably affect patient care in the sense that it would remain superficial and lack continuity, as it is only ever based on the issues that are presented and discussed during that particular visit. Due to this, she emphasised the importance of inquiring as to any concerns and problems that patients experienced between appointments, as has been discussed in the previous section of 4.2.2.

> *I met with a different person on each visit. Sometimes, they wanted me to repeat the problem again, which sometimes made me fed up. I also have no idea what my problem is. I was like, "Read for yourself"... If we meet the same person, maybe we can tell her/him that, "Doctor, after I took the medication that you prescribed last time, I felt like this and this". But when we meet with a different person, she/he will say, "You just continue the same medication that we prescribed". So, we just continue. "So far I can see that you're okay and everything is normal". So, we'll be like, "Okay no need for me to tell anything, just go back". They don't provide us with any guidance. No guidance is given about anything. (PT12, 29-year-old, Malay woman, HC)*

The excerpt from PT12 serves as a further indication of the disadvantages of patients meeting different HCPs in their appointments. PT12, who does meet with the same

person on each visit, experienced frustration and confusion about her health problem, as she continued to be asked the same questions on each visit by different physicians and diabetes educators. As a result, this patient perceived there to be no visible and satisfying result from the management that she received. This seemed to lessen her interest in playing an active role in further discussing her problems with the HCPs, which was similarly identified by Joseph-Williams, Edwards, & Elwyn, (2014). This is not an isolated case, however, as, throughout the analysis, the situation faced by PT12 was found to be common and shared by many patients in this study when it came to meeting different HCPs, particularly physicians.

> *When you see them more frequently they will treat you as a friend and they will tell you. Like sometimes, they inject everything okay, so I'll ask them, "How's your diet intake?" "Sometimes when I go out and hang out with my friends, I'll take sweetened milk tea and all that". (HCP9, pharmacist, CC)*

The above excerpt by HCP9, on the other hand, demonstrates the advantage of a patient's management being handled by the same HCPs for a long period of time. Similar to HCP19, this DMTAC pharmacist has the luxury of meeting the same set of patients, which she further described as smoothing the information exchange between both parties, especially when it comes to identifying a problem at the beginning of their encounter as they are already conversant and comfortable with each other. This is because multiple encounters with the same HCP will facilitate a better, long-lasting relationship between the patient and HCP, which in turn makes a significant positive contribution to the development of highly trustful health interactions over time (Riva et al., 2014; Dardas, Stockburger, Boone, An, & Calfee, 2016). Thus, it will further help the HCPs to gain a more comprehensive understanding of the patients' disease progression, as they have the opportunity to discuss the decision that was made in the previous appointment and are also able to further discuss any decisions that were not made. This continuity of care is very important in the management of T2DM as it helps to ensure that patients

continuously adhere to a way of managing the condition that they are most comfortable with.

> *We do, but again, that's a very beautiful word, but it doesn't work when you have resource constraints. So that's what I mean. Personalised care is when those with uncontrolled diabetes are supposed to go back to the same MO for them to follow up and all that, but we are very short of doctors at the moment. Only a few days ago there was an argument between an MCH doctor and OPD doctors. Who has to cover who? Because we have the MCH running as well. It's the same pool of doctors. We don't have separate pools of doctors, no, unfortunately we don't. Because of that, when there's so much in the way of resource constraints, when we are very short of doctors, sometimes even now the appointment rooms are also open as OPD rooms, you know. (HCP15, family medicine specialist, CC)*

However, this is not easily achieved, especially among medical officers and for professionals who work on a rotation basis, such as diabetes educators, pharmacists and dietitians, who have to cover more patients compared to other professionals. It becomes even trickier for medical officers who have a greater number of patients and who are responsible for the overall management of their patients. With this realisation, an approach known as personalised care was introduced at one of the study sites in a bid to enable diabetic patients to be seen by the same medical officer on each visit. However, according to HCP15, despite the usefulness of this approach in fostering mutual familiarity, continuity of care and more effective consultation, it was a challenge to continuously employ this approach due to the high patient/primary care physician ratio and shortages of other resources in the clinic.

> *If they met other person, they might not feel comfortable as they're not used to it, but sometimes they don't want to try. The problem with the patients they do not want to try with other doctors and probably the doctor is better than me. So there are still options, but sometimes, when I look at the patients, they know you, they like you and then they, they don't want to trouble themselves to meet other person. But, on and off, for example my patients, sometimes, they need to see other doctors… not just for second opinion because the doctors that haven't seen them will look from different angles, compare to me, sometimes I've assumed, "Oh I know this patient very well" and sometimes, few things seemed to not triggered you, you know. For example, I know you very well, so I say this and this, but when other people see you, they will say,*

"Eh, why you look different?" Because when we see them, it's like when your parents see you every day. So, I think they should. That's why, if I'm not around, I allow any doctors to see them because I believe that probably there will be extra input that will help the patients. (HCP18, endocrinologist, HC)

In contrast, however, it may also be beneficial for patients to meet other HCPs, as this can bring new perspectives to the patients' T2DM management. HCP18, in her account above, believed that other HCPs would view a patient's problem and condition with a fresh set of eyes and a different perspective, which would result in a different management recommendation. A study by Frongillo, Feibelmann, Belkora, Lee and Sepucha (2013) further asserted that these patients tend to be more involved in making a decision as they have access to a more balanced discussion on the different options that are suitable for their health condition. However, HCP18 also posits that this may not be easy among patients as they tend to be reserved with people with whom they are not familiar, in addition to refusing to meet other HCPs, thus meaning more effort is required to connect and interact.

4.2.5 Language barrier

As mentioned earlier in the introduction chapter, Malay is the national language of Malaysia. Nevertheless, not all Malaysians are well versed in the language due to the country's multiracial society. Despite English being the national second language, there are Malaysians who lack proficiency in both languages and who are fluent only in their native language. This is especially the case among the elderly population or less educated non-Malays, which is mainly due to ethnic segregation in Malaysia's education system (Raman & Sua, 2010). Examples of situations where the language barrier was a factor can also be found in this current study.

Language is very, so tired. So, I will say the words one by one and the simplest ones. And what they can do, and for those cases you have to do it one way. We can't discuss at all, because they can't, their vocabulary is very limited. For those cases, I'll ask what they eat. I will still do the diet recall despite the barrier… But we also know some of the food. Like oats, they call it 'makpin', kidneys they call it 'yuchi'. (HCP10, dietitian, CC)

> *If they have a problem they will tell. It's just they can't really speak well in Malay. So, this is the main issue for the elderly and less educated. If you use simple Malay, still okay, but if you ask more, maybe they can't really give the answers the doctor want. Sometimes the doctors ask questions, I'm not sure how the doctors ask, but sometimes maybe they can't understand. Sometimes, some doctors are quite good, they'll write down language barrier with patients and certain thing doctors ask patients, they don't understand they will write down there, "Please confirm these with this patient" and then the doctor will write language barrier. So, we'll ask back, "How you take this medication? Doctor wants to know whether you take correctly or not." Quite a few numbers. Because we have a lot of elderly. If the children come together with them, okay. But those who come alone, or both also very elderly ones, husband and wife, a bit difficult. (HCP9, pharmacist, CC)*

As a multi-ethnic country, the different languages spoken and different levels of proficiency between patients and HCPs were found in this study to constitute a prominent barrier to fostering shared decision-making as they complicated information exchange. Despite there being an intention to communicate and discuss patients' concerns and problems, the information exchange seemed to be extremely challenging and impaired, especially in cases when the patient and HCP were from different ethnic backgrounds. Comparable with the findings of previous studies involving multi-ethnic participants, the descriptions by HCP10 and HCP9 demonstrate their difficulty in exploring patients' problems and in having a more in-depth discussion on their condition due to the language barrier (Patel, Stone, Chauhan, Davies, & Khunti, 2012; Renfrew et al., 2013).

Nonetheless, realising the negative impact of the language barrier, these HCPs attempt different methods to overcome the problem, including learning important words and phrases that may encourage further information exchange and patient participation, referring the patients to another HCP from a similar ethnic background and encouraging a family member who is proficient in either Malay or English to join the consultation. These efforts may thus reflect an improvement in terms of Malaysian HCPs' reception and their embracing of their patients' contribution to the making of T2DM management decisions (Eckhardt, Mott, & Andrew, 2006; A. Ho, 2008).

However, there is no evidence of this in the patients' data; this may be due to the fact that patients who are not proficient in either Malay or English are excluded from this study. Haron and Ibrahim (2012) found that almost half of the patients in their study preferred to be seen by HCPs of the same ethnicity and with a similar linguistic proficiency as this eased communication and understanding (Kim et al., 2000; O'Daniel & Rosenstein, 2008). Yet again, it would be difficult to assign patients to HCPs from the same background and this approach is deemed to be ineffective in the following account by HCP5 due to a lack of manpower. A similar concern was also raised by the participants in another Malaysian study by Y.K. Lee et al. (2012), where it was reported that they did not have enough Indian staff to cater for their Indian patients.

> *It's hard to imagine what will happen if we do that. I can't imagine. Because, we only have one Chinese doctor here, so we can't expect her to see all Chinese patients. (HCP5, medical officer, SC)*

4.2.6 Section summary

The findings and discussion in this section demonstrate a mismatch of expectations between patients and HCPs with respect to the assessment aimed at identifying the problems to be addressed. Despite being emphasised as an element in the management of patients with T2DM (Chew, Vos, Mohd Sidik, & Rutten, 2016) and supported by the assertions of the patients in this study, patients' psychosocial problems are clearly not one of the main agendas that HCPs have in mind in managing their patients with T2DM. The HCPs' lack of concern in this matter might be because patients with T2DM will be provided with on-going care, thus 'non-urgent' and 'non-clinical' problems can be dealt with later as they face time pressure in terms of managing all of the patients who come to their facility. Besides, the focus given by most of the HCPs to patients' biomedical status seems to prevent them from further exploring the roots of the patients' problems, which were commonly related to psychosocial factors and required active engagement on the part of the patients. The participants also highlighted meeting different individuals and the language

barrier, which can be related to the patient–HCP interpersonal relationship and communication.

4.3 Information and recommendation

This section discusses the findings that relate to two essential elements in a shared decision-making model – presenting options and HCPs' recommendations. The following four important issues emerged for these two elements: (1) The role of HCPs: giving options, recommendation or instructions?; (2) Sequence of options; (3) Missing information by the HCPs; (4) Patients perceive they have no other options.

4.3.1 HCPs' role: giving options, recommendations or instructions?

> *If we feel that a particular treatment is suitable for patients, but if we have limits based on our quota or budget, we still offer them alternatives. They can purchase the medication outside. It's not to say, "No, we don't have the stock, you cannot continue"... Because now, as of now, diabetic medication is so advanced, there are so many ways of treating it, if there is a new drug out there that is suitable for them and might help achieve very good control, we will advocate it and if we don't have the facility, we'll offer them an alternative or an option to purchase on their own. (HCP17, medical officer, HC)*

HCP17 is among the HCPs who mentioned that, apart from offering options that can be provided in the facility, patients also have the choice to opt for a medication that they can obtain outside the facility. However, this may not suit every patient, as not all patients will be able to afford outside treatment or medication, which is mainly provided by the private sector. This will cost them more compared to treatments that they can access from government-funded facilities, for which there is usually only a minimal charge. Nevertheless, this also illuminates the complexity of the healthcare system in Malaysia, which can be both advantageous and detrimental to the management of T2DM in general and to the implementation of shared decision-making specifically as it involves both the private and public sectors. Although a wider range of T2DM treatment and management is offered by private health facilities in Malaysia, they, unlike the public health facilities, are not subsided by the

government. As such, the much more comprehensive T2DM management at private facilities can only be accessed by patients who can afford out-of-pocket payment (Thomas et al., 2011).

> *We'll provide them with alternatives. Okay, even though we know that the food is not healthy, but I know, we want them to be functional, and a little bit happy. (HCP13, dietitian, CC)*

The claim resonates in the account from HCP13. In helping patients to adapt and adhere to their lifestyle modification, especially a healthy diet, HCP13, as a dietitian, presents what she considers to be acceptable choices, which, although they may not always be considered the healthiest, are nevertheless acceptable for the patients. This provides patients with a greater array of choices and enables them to make an informed decision when they are at home and have no immediate access to their HCPs. Yet, similar to most of the cases, HCP13 is more likely to present these options to her patients if the option that they recommend is more expensive. However, she still considered that her recommended option is the best option for the patients and viewed other options as inferior to the recommended one.

> *…in certain conditions, for example, we say, "Okay, I've increased your dosage". So, they have to follow, they must follow that. But in terms of sugar monitoring, I'm more flexible. So, I will not say, "You do this, you follow this". It is not necessary for that. I'll ask, "Are you okay with this? Do you agree to do it like this?" But in terms of insulin dosage, adjustment, we want them to follow us. So, it depends, it depends on what the decision is and it depends on the condition. (HCP7, diabetes nurse educator, HC)*

The above account by HCP7 is one of the examples of common practice found in this study. Similar to many HCPs, HCP7 tends not to provide patients with an option or even ask for their agreement when it comes to their medication, especially when it comes to the option that the HCP considers to be the best fit for the patient. HCP7 also clearly prefers to take a paternalistic approach, with her interactions with patients entailing them being informed of their medication dosage and given

instructions to adhere to, as opposed to information being provided and then discussed, which will be further explained in section 4.3.2 of this chapter. On the other hand, HCP7 did consider patient involvement when it came to determining the frequency with which they performed SMBG and enquiring as to their opinion and agreement. This corresponds with the previously discussed practice by HCP13 and in the study by Wens, Vermeire, Royen, Sabbe and Denekens (2005), where it was found that different options were more commonly discussed when deciding on non-pharmacological management relating to the patients' environment, cultural and social status. In this case, the recommended practice of SMBG requires patients to buy their own glucometer, strips and lancets, which contrasts with those pharmacological modalities in which most of the medications and related equipment are provided by the public health facilities in Malaysia.

The presenting of options to patients is considered to be important as it is believed to boost equity in the use of and efficiency of the healthcare services (Fotaki, 2014). However, Dixon and colleagues (2010) suggested that patients who are offered too many options may experience dissatisfaction with the one they are forced to choose, arising from their limited access to the other options. This limited access may stem from many factors, including their inability to afford any of the alternatives. This was referred to by Schwartz (2000) as the 'tyranny of choice' and it may further diminish the power or capacity of patients to act (Bourdieu, 1977). Being presented with different options may actually benefit neither patients nor HCPs, especially when the patients are not fully equipped with the requisite support and information to enable them to weigh the 'pros and the cons' of each option that is presented to them (Boyle, 2013).

A lack of different options being offered by HCPs was also found in the data collected from the patients. Most of the patients admitted that there were no, or very few, occasions when options other than the recommended or prescribed one had ever been presented by their HCPs.

Look at this, she added another 2, it becomes 20… Injection. That's what I said just now, when I see them, the injections will increase. They will add… It's just my diabetes, 10.7. It can be considered borderline, 10. I don't know how they calculate it….But, actually, I thought to myself, I'm not, I hope that the doctor's medication will be good, but I used to stay at the night market, I sat there and I saw a lot of traditional medication, I also take it, but I take the ones with, not the ones without, I take the certified ones. (PT15, 59-year-old Malay man, CC)

Then, he even added the frequency. Haaa, can you see? He's adding my problem. I'll feel even more pain. Then, I asked for other oral medication but I saw that he didn't really check. There must be other medications that I haven't tried yet. There must be a lot, right? For me, there must be a lot. But it might be limited and my condition is not that bad. So, they prioritise people with worse conditions. (PT22, 34-year-old, Malay woman, HC)

PT15 and PT22, besides having their medication added paternalistically, believe there was a lack of discussion regarding their condition and that insufficient information was given to them regarding the change of their prescription. Despite having a positive perception of the reason for the aforementioned practices of his physician, PT15 also seemed to have a lack of understanding of his current T2DM management. This may be among the reasons why he considered traditional medicine, which is popular among Malaysians as an alternative means for treating their health problems (Siti et al., 2009). Besides, Malaysians are more exposed to this type of medication due to the ease with which it can be accessed and the widespread direct-to-consumer advertising in comparison to that for conventional medication (Chin, 2005).

If we can share the information with them and they can understand you, actually they can follow. Maybe they didn't agree with the recommendation because they don't give the information or they listen to their friends. This is the main problem. A lot of patients said, "my friend said…". (HCP9, pharmacist, CC)

Furthermore, based on health-seeking behaviour, if T2DM patients are deprived of the opportunity to seek alternative options and related information, this can often lead to a greater tendency for them to seek it from other sources, such as from their family and friends (L. L. Low, Tong, & Low, 2016). These patients are also more

easily attracted and persuaded by this information compared to the information that they receive during encounters with their HCPs, as was evident in the above accounts by PT15 and HCP9. This is more apparent in the collectivist Malaysian culture and in situations where long-term trustful relationships cannot be formed for reasons such as those previously discussed in this chapter. This lends support to the importance of discussion being held with patients, which has also been further found to be strongly associated with patients' non-adherence (Chao, Nau, & Aikens, 2007).

Similar to the finding by Hajos and colleagues (2011), PT22 would appreciate being offered different options and related information to consider. However, due to the lack of options presented to her, she began to question her physician's paternalistic decision to increase the medication dosages, which may indicate her lack of trust and confidence in the physician's professional judgement. This tendency was also evidenced in the findings of Price, Bereknyei, Kuby, Levinson, and Braddock (2012). Added to this was her physician's refusal to enter into a further discussion regarding her query about other oral medications and the physician's ignorance towards the reported effect of her current medication, which further fuelled her scepticism regarding the physician's intention to provide treatment that best suited her condition. Yet she also understood that there may be only limited availability of other options in the public health facilities and that there are also other patients whose need for these options is greater.

4.3.2 Sequence of options

The management of T2DM involves complex interactions between biological, psychological and behavioural factors of care. Additionally, advances in medical technology have led to a wider range of pharmacological modalities for diabetes (Tahrani, Bailey, Del Prato, & Barnett, 2011). However, as mentioned in 4.3.1, the analysis has shown that it is unusual for options other than the recommended one to be presented to the patients in this study. It is also found to be common for the HCPs to present the other available options if there is a problem with the recommended one.

> *Usually I will ask them first, "Can you do this every day?" If they can't, we'll make a deal. If they can't do it, they can do it on alternate days or every 3 days… There are a lot of options, which means we don't force our patients to do exactly what we say. They do have other options. (HCP8, diabetes nurse educator, HC)*

In the above account, HCP8 states that options will be presented if a patient is considered to lack the ability to carry out the suggested or prescribed management. Such patients will not be forced to carry out their SMBG every day as recommended by the Malaysian CPGs (MEMS, 2016) but will instead be presented with other options that may suit them better. Yet the practice of such options being presented only after patients are deemed unable to perform the recommended option, or they disagree with it, may reduce the possibility of all available options being given to all patients in the first instance for them to thoroughly consider and evaluate. According to Beauchamp and Childress (2013), this is another form of paternalism as it may introduce bias since patients might form the impression that they have no option other than the recommended one, as further explained in 4.3.4.

In other cases, alternative options will be given to patients who face problems with treatment that has previously been prescribed paternalistically by their HCP.

> *Sometimes, there are complaints, "it's hard for me to take it twice". They'll tell us. And we'll try to adjust it. Usually it depends on the patient's condition. (HCP11, medical officer, CC)*

Based on the above account by HCP11, an adjustment is made for patients who are struggling with their current treatment. Most of the time, and similar to the previous account by HCP8, only one option will be presented initially, meaning this cycle will continue. Some patients will never be aware of or have access to these other options as they have not shared their problems based on a belief that there are no better alternatives for managing their T2DM. For others, as mentioned in the previous section, their problems and needs are not thoroughly assessed. This may pose a significant challenge for the patients as they have insufficient opportunity to assess

and evaluate each available option prior to agreeing with the HCPs' recommended treatment or opting for something else (Elwyn et al., 2012). Besides, presenting only the recommended option may serve as a good but subtle indication that the HCPs still maintain the belief that their recommended option is the best for patients. This is discussed further in section 5.3.1.2 of the next chapter.

4.3.3 Missing information by the HCPs

At times, whether the patients were presented only with the recommended option or different available options, the gathered data revealed that HCPs were generally not fully transparent and unbiased with their patients in terms of the information they shared.

> *Okay by right, CPG HBA1C more than 8 they are supposed to be on insulin. But doesn't work that real. Not everybody is going to do that. So over here in this setup, we have only 2 types of medication. Metformin and Gliclazide. Once they're at maximum dose, we really don't have other grousp high tech medication. So, we have to go with this. We use our resources. So, the next option will be insulin. So, we have to convince them…' HCP12, medical officer, CC*

> *One more thing is, insulin is adjustable. If they take oral medication, they can't adjust the dosage, but they can do this if they're on insulin. So, their sugar will decrease and their sugar level can be controlled in the normal range. Usually we'll make that sort of comparison. When we tell the patients that they can adjust the insulin dosage, they will like it. As compared to oral medications, if the prescription is one tablet, they can only take one tablet and they can't adjust it by themselves, whatever happens. For insulin, they can adjust it based on their diet. So, patients will be more open. (HCP6, diabetes nurse educator, HC)*

Based on HCP12's account, the HCPs' recommended option is usually made based on the Malaysian CPGs for T2DM. To reiterate, the CPGs promote the early optimisation of diabetes medications in an effort to achieve glycaemic control and prevent complications (MEMS, 2016). This includes the early initiation of insulin among patients, especially among patients who are struggling to control their

glycaemic level. However, similar to patients in other parts of the world, Malaysian T2DM patients often have a negative perception of insulin and prefer to manage their T2DM using all other available means, including complementary therapies, prior to starting insulin therapy (Peyrot et al., 2005; Y.K. Lee et al., 2012). Between this and the lack of treatment options available at the study sites, the information presented with regard to deciding upon insulin initiation is often geared towards convincing patients to agree, as illustrated in the above accounts by HCP12 and HCP6. The account from HCP6 further shows that even though this nurse stated that she made a comparison between the oral medications and insulin, she made a point of only emphasising the advantages of insulin injections, with no mention of the advantages of oral medication. This may serve as an indication that the options were not presented equally, as suggested by the shared decision-making model (Makoul & Clayman, 2006). Comparable to this is a study by Guerrier, Légaré, Turcotte, Labrecque, and Rivest (2013) which found that among HCPs with prior training on shared decision-making, their intention to follow the CPGs often reduced their intention to engage patients in shared decision-making.

> *…we'll tell them about the medication and all but we're lacking in terms of side effects of the medications. We don't have enough time to explain in detail and we'll hand it over to the pharmacist. Usually, we'll explain about the medication that we have prescribed and why they have to take it and all, but not so much information about the drug itself. Because the pharmacists are the experts on that. (HCP11, medical officer, CC)*

> *Actually, all of that should be told, but I'm not sure, and I don't want to blame anyone. But then we also don't know whether our patients are having side effects after the prescription or not… Maybe that's why sometimes when the patients have no courage to tell. They stopped the medication by themselves. They stopped and then we ask whether they take their medication or not and we'll ask in detail. If they tell us, "I stopped taking it a long time ago", then we'll ask them "Why?" They'll tell us, "Abdominal discomfort". So, that's one of the side effects of the prescribed medication. So, we'll say, "Actually that medication is good but if the patient is experiencing any side effects from it, we'll recommend other medication but from the same group". (HCP14, medical assistant, HC)*

The analysis of the data in this study also demonstrates that it is common for patients to not be fully informed about the possible side effects of the recommended medications, as illustrated in the above accounts by HCP11 and HCP14. A study by Sibley and colleagues (2011) had similar findings in that concerns about medication, including side effects, was one of the elements least frequently discussed during prescription despite it being the issue most commonly raised by the patients. According to Latter, Maben, Myall & Young (2007), this is frequently associated with a covert effort by HCPs to obtain the agreement of patients. Furthermore, a lack of discussion on the negative effects of the recommended option may be a way in which HCPs seek to maintain control over both the ability of their patients to choose and their behaviour, as asserted by Lanceley (1985) and Laverack (2005). In this study, although it may appear that they are providing their patients with a range of options for consideration, the way in which the information relating to these options is presented is often subtly shaped by the HCPs so that patients will tend to agree with their recommendations as opposed to using their own free choice based on the presentation of unbiased information from their HCPs.

However, the above accounts by HCP11 and HCP14 also demonstrate misunderstanding between different groups of HCPs in terms of the responsibility for providing such information to patients. Based on HCP11's account, information on the prescribed medication may not be fully discussed by physicians as they believe that further discussion will take place between the patient and the pharmacist. Yet many non-physician HCPs, including the pharmacists, perceived this to be the responsibility of the physicians as part of issuing the prescription, as asserted by HCP14. This confusion with regard to the responsibility for informing patients about one of the most important aspects of the medication serves as evidence of the complexity of involving different groups of HCPs and points to the need for considerable effort and cooperation from all (Gucciardi, Espin, Morganti, & Dorado, 2016).

In addition, the lack of attention to information on the side effects of treatment serves as a possible indication of HCPs' belief that medication-related side effects are often exaggerated (Williams, Manias, & Walker, 2008). As a result, much important information regarding the chosen treatment fails to reach patients, along with a lack of presentation of other available options. HCP14 also mentioned that most patients were reluctant to or did not share problems they faced with their medication, which may be due to the way information about it was communicated to them (as explained in 4.1.2), or because the information was never presented to them in the first place. Typical consequences of this are prolonged self-modification or discontinuation of a course of medication, as illustrated in the above account by HCP14 and the below account by PT12.

> *PT12: She just asked me to try the medication. She said because my sugar is high, 'So you try this medication.' Then I took it once, but I wasn't feeling very well, so I stopped.*
>
> *R: How long have you stop the medication?*
>
> *PT12: Quite long as I only took it once. That's why I needed to admit to the hospital as I wasn't feeling very well. (PT12, 29-year-old, Malay woman, HC)*

PT12 is one of many cases in which medication was prescribed paternalistically with neither a presentation of the other available options nor any discussion on the prescribed medication. This is in contrast to the assertion by Heisler and colleagues (2003) that patients who agree with the recommended management receive better information as that form of management is thoroughly discussed by the HCPs. Due to a lack of information, PT12 ceased taking her medication after only one dose. She then sought no further help despite finding information on the Internet that the symptoms she was experiencing were consistent with those of the side effects of her medication. This account is comparable with previous studies in which patients who were found to lack knowledge about their management, including their medication, displayed a greater tendency for non-adherence (Chao et al., 2007; Nair, Levine, Lohfeld, & Gerstein, 2007; Aiken & Piette, 2009; Gimenes, Zanetti, & Haas, 2009; Shariful Islam, Biswas, Bhuiyan, Mustafa, & Islam, 2017). Two months later, this

patient was admitted to hospital with pneumonia, which is a common complication in uncontrolled diabetes (Torres, Blasi, Dartois, & Akova, 2015).

> *No, no one has ever mentioned about the side effects of my medication. But we know, there are chemicals or substances that enter our body which can cause our kidneys to work harder I understand that and that's why, in the beginning, I just couldn't accept that I had diabetes, as I couldn't accept that I had to take medication. (PT11, 36-year-old Malay woman, HC)*

> *I have to eat brown rice, right. As for wholemeal bread, sometimes I can't take eat it anymore, as I'm eating it too often. Sometimes, I just can't control…I don't know how to ask. Don't know what to ask. (PT7, 47-year-old, female, SC)*

In the case of PT11, the lack of information from HCPs led to her generalising her existing knowledge of the side effects of her previous medication and subsequently applying this knowledge to her newly prescribed medication. This further underscores both her need and right to receive unbiased, sufficient information, including the potential side effects, of all suitable management options. The findings by Mann and colleagues (2009), supported by DiMatteo, Haskard-Zolnierek, & Martin (2012), demonstrate that a failure to fulfil patients' need for information is likely to encourage their non-adherence. Such non-adherence can also be sensed in the above account by PT7, which may be due to her lack of understanding regarding the advice given by her HCPs. Besides, similar to many of the patients in this study, PT7 admitted that she did not enquire further as she was unaware with respect to what to ask for and how to ask for it.

> *Like just now, he only said, "Liver okay, sugar high". He only said that. I said, "What is the (sugar) reading doctor?" Then he opened back, "For the 3 months test is 11, and the fasting sugar today is 13". "How about my liver?" "Liver is okay, in the normal range". Then I asked, "What is the value where the liver no longer okay, doctor?" So, I'm the one who asked a lot of questions. If not he only said to me like that, "Liver is okay, sugar for 3 months is high". Then I wasn't satisfied, he opened back because I asked him. He just clicked for himself, not for me. (PT22, 34-year-old Malay woman, HC)*

However, there are also patients who will ask for the information they need, as illustrated above in PT22's account. PT22's enquiries were made with the intention of obtaining a better understanding of the T2DM condition and its management. This is aligned with the evolving culture in Malaysia in which Malaysian people are no longer comfortable with ambiguity and are becoming increasingly concerned about their future (Hofstede, 1984; Ken & Ying, 2013). Thus, in this study, the increased Malaysian score for uncertainty avoidance can be translated into patients wanting more knowledge and information to help them navigate their T2DM management and avoid both its side effects and complications. Supporting the importance of this, previous studies have also found that most of the patients involved believed that they needed this information and that their HCPs should not withhold it (Ziegler, Mosier, Buenaver, & Okuyemi, 2001; O'Brien et al., 2013).

4.3.4 Patients perceive they have no other options

The analysis further reveals that due to the way information on different options is delivered, as explained in 4.3.1, 4.3.2 and 4.3.3, some patients feel they do not have any option other than to acquiesce to their physician's recommendation, even in situations where they have been presented with other options.

R: So the doctor did give you choices? The other choice is another oral medication?

PT2: Add another oral medication, but it is not advisable because it will damage the kidneys. Actually, the medicine that I'm currently on is also bad for the kidneys, but if I add another one, it will become worse. So, she advised me not to do it. So, the doctor suggested that I go for insulin, and though I really don't like it, I have no choice...

R: So you have to take the oral medication together with insulin? Or just the insulin?

PT2: No no no. They are giving me the medication and also insulin. So, I wonder, why they are giving insulin and the medication.

R: Did you ask the pharmacist or doctor during your consultation?

PT2: No, I will ask her after this. That thought just came to me only. I didn't, but they are giving me both? The doctor also wrote it. (PT2, 61-year-old Indian man, SC)

PT2 did not consider any options other than the one that was recommended. For PT2, this perception may have developed due to a combination of the aforementioned reasons and his trust and high regard for the physician's expertise, a factor that is also mentioned in 4.3.1. This led to the patient choosing to agree with the HCP's recommendation to start on insulin, which he actually rated as his least preferred option despite also being presented with his preferred option of adding another oral medication. Similar to the recommendation of the existing model of shared decision-making, a degree of tolerance needs to be shown by both sides when seeking to determine the best option for the patient, which also means there is always the possibility of either side's preference not being fulfilled (Makoul & Clayman, 2006). Yet, as asserted previously, sufficient information needs to be given to patients in order for them to have the comprehensive understanding needed to reach this kind of decision, which could be described as less preferred and difficult yet necessary (Elwyn et al., 2012). In this case, the information shared by the physician may be considered as deficient and biased, with the previous excerpt revealing that PT2 had a misunderstanding concerning his pharmacological modalities. He was under the impression that he would no longer need to take his oral medication if he started on insulin. However, this was not the case as he was still required to take his previous dosage of oral medication in addition to the newly prescribed insulin.

... they did tell me what food I should avoid. There's a lot. Even the rice, I only can take one-quarter of the plate. It's too little. Sometimes I just eat one whole plate and I even add some more. They also advise me not to take curry, rendang, coconut milk, sweet sour and all. They asked me to only take broth. That's it. But I don't follow. They even ask me to avoid paratha. They said only once a week. But I just ate everything. (PT21, 66-year-old, Malay man, CC)

PT21, on the other hand, as outlined above, considered that he had no choice but to strictly follow the advice given by his HCPs due to the lack of explicit food options and the way in which related information was given. Consequently, this patient opted

to completely disregard the advice as he felt it was too difficult to follow. These two accounts serve to strongly indicate that neither patient was fully informed of the treatment options or able to thoroughly discuss them with the HCPs. This finding also supports the suggestion that it is important for all of the available options to be fully discussed and for patients' preferences and values to be thoroughly explored prior to HCPs giving their recommendation (Robinson, Callister, Berry & Dearing, 2008; Sandman et al., 2012).

4.3.5 Section summary

Overall, the findings discussed in this section indicate that the practice of information provision is lacking among the HCPs. The findings from this study are similar to those of Aasen, Kvangarsnes, and Heggen (2012), whereby the HCPs often shaped the information given to the patients so that they would agree with their recommendation or prescription, instead of facilitating discussion on the most suitable option for the different patients. HCPs will do this by presenting the recommended option prior to other options and by providing insufficient and biased information regarding the options. This is especially the case in relation to decisions on patients' pharmacological modalities compared to other forms of T2DM management. Due to the way in which the options, related information and recommended choice was presented, most patients felt compelled to agree and then encountered difficulties in carrying out the chosen T2DM management on a daily basis. Besides, the patients in this study appeared to want more information about their management and the other options available for their own T2DM case. However, due to a lack of skill and knowledge, their need for information was not typically shared with their HCPs. Finally, when it comes to the presentation of the available options, risks and likely benefits in terms of the heightened opportunity for patients to be involved, there are some dissimilarities and inconsistencies in the overall data.

4.4 Discussion and deliberation

Charles and colleagues (1997) asserted that the presentation of all of the suitable treatment and management options and their potential benefits and side effects is

crucial to allow patients to evaluate and deliberate, in addition to enabling them to develop their ability to self-manage their T2DM. Following the findings presented in the previous section 4.3 on the lack of presentation of options and related information, the analysis also found that there was a lack of discussion and deliberation in making decisions for T2DM patients at the study sites. Besides, only a small handful of the HCPs elicited and discussed their patients' preferences and values in an effort to ensure that the chosen option matched their preferences and values. This section presents and discusses the following two important HCP practices pertaining to discussion and deliberation: (1) deliberating or persuading patients to agree?; and (2) flexibility and compromise with patients.

4.4.1 Deliberating or persuading patients to agree?

The data in this study reveals that most of the HCPs' deliberations with their patients were geared more towards seeking patients' agreement with their recommendation, as shown in the accounts from HCP12 and HCP5 below:

> *Usually you have to ask them why, we'll explore why and then I'll try to re-counsel them. Try to reason with them, try to show them, "you see all of this is happening, your sugar is just going up, you're gonna get complications soon". Usually I will count the risk score in front of them and say, "Okay madam you see you are at so-and-so risk of having a heart attack". So, once they understand they become receptive, but some still don't want to. We have to persuade them repeatedly because, as I say, we don't really have many treatment options. Reasoned with them. (HCP5, medical officer, SC)*

> *...but the most important thing is we have to get their agreement. (HCP13, diabetes nurse educator, CC)*

Similar to the findings discussed in section 4.3.2, HCPs evidently often persuaded and convinced patients to agree with their recommended treatment, especially with regard to starting on insulin therapy. This is more aligned with obtaining patients' consent (General Medical Council, 2008; Malaysian Medical Council, 2016) than it is with any shared decision-making, which would involve elicitation of the patient's

preferences and values so that these could be taken into account when making the decision (Makoul & Clayman, 2006; Elwyn et al., 2012). This is further discussed in section 5.3.1.1.

HCP5 continued to discuss the reasons for patients' refusal of the recommended treatment, in this case commencing insulin therapy, and emphasised the benefits it would bring in terms of controlling their glycaemic level and preventing complications. Rather than being overly concerned with ensuring patients truly understood insulin as a form of treatment, most of the HCPs were more concerned with ensuring patients agreed to begin using it, which often resulted in the sharing of biased information. Loewenstein, Brennan and Volpp (2007) termed this practice asymmetric paternalism, whereby discussion of the available options was shaped by the HCPs in order to direct patients to the recommended option while at the same time not depriving them of their right to other suitable options and the related information. Politi, Lewis, and Frosch (2013) suggested that this practice is common when there is little in the way of clinical evidence as to the effectiveness of other options. As such, a similar practice of persuading and convincing patients was found across the data, even with the non-physician HCPs. The excerpt from HCP9 below is one such example.

> *I can't say we can make together, but sometimes we can ask patients' opinion. But making the decision together I think we must convince the patients to follow the treatment the doctor wants to give. If we can share the information with them and they can understand you, actually they can follow. (HCP9, pharmacist, CC)*

4.4.1.1 Perceived intimidating messages

On many occasions, some of the patients believed that as well as not having enough discussion on the decision to be made, they mostly felt pressurised or even intimidated by their HCPs to agree.

Sometimes when we have to say, "If your sugar is continuously like this, the doctor said to me that she wants to discharge you from this hospital. We are the specialist hospital here and if your sugar is still not controlled it means that we've failed in managing your diabetes. So, you can go back to the health clinic, we discharge you. Do you want that?" We say it like that and only they'll be like, "Oh okay". (HCP7, diabetes nurse educator, HC)

She threatened me. I'm not really keen on the way she delivers the message, "If you feel that you that you want to pregnant, you have to reduce your weight". It's like she threatened me. But the message didn't come across. I don't really pay much attention to her after that. (PT12, 29-year-old, Malay woman, HC)

The above accounts reveal that these intimidating messages were not only in the form of the most serious and feared complications but also included the consequences that the patients may have faced if they did not agree with what the HCPs perceived to be the best option for them. The excerpt by HCP7 provides an example of the way in which the HCPs communicated this information. This will most probably further reduce patients' intention to become involved in a discussion about their health decision in addition to them being intimidated by the complexity of the decision-making process (Frosch & Kaplan, 1999). The perception of these messages as threatening can be detrimental for some patients, with PT12 as an example. PT12 admitted to being likely to disregard such emotionally charged messages despite being aware of their significance (Lawson, Bundy, & Harvey, 2007; Matthews, Peden, & Rowles, 2009).

Their high voice is one thing. It's the tone of their voice. The doctors should be more prudent. They should not intimidate people. Cut their legs, insulin and all. (PT18, 55-year-old Malay woman, CC)

Additionally, as mentioned in subsection 1.5.1, Malaysia is a society with high-context communication in which implicit communication, which includes tone of voice, facial reaction and body gesture, is as important as direct communication (Hall, 2000). Thus, the complaint from PT18 is not unusual and is actually one that is shared by many of the patients in this study. It may thus be acting as a significant

barrier to patient involvement in decision-making for their T2DM management. It would also appear from PT18's excerpt that insulin initiation is used by HCPs as a way of intimidating patients. This may lead to patients developing bad misconceptions with regard to this pharmacological modality and may also influence their preference and practice of it in the future (Brod, Alolga, & Meneghini, 2014).

> *Usually, we'll re-counsel them. We have to explain why we want to start insulin. We have to draw the picture of pancreas and everything. There is impairment here, you might have to do dialysis and all. We threaten them a little bit. For some patients, it has been so long since the first time it was suggested for them to start on insulin. They've been talked about this by the staff for quite sometimes and they keep on rejecting. (HCP11, medical officer, CC)*

Nonetheless, in further investigating this approach from the HCPs' perspective, it was found that they tended to use it owing to a frustration with their patients' stubbornness. They may therefore have felt the need to be a little more aggressive with their patients in order to get them to agree with their recommended management, as was also identified by Wens and colleagues (2005). Similar to the study by Wens and colleagues, the accounts from HCP7 and HCP11 in this subsection reflect the HCPs' belief in the effectiveness of this approach as one that would put pressure on the patients to agree and comply with the suggested option despite the potential for a fall in both their satisfaction and perception of self and identity (Hornsten et al., 2005). However, C. Price (2009) argues that this pressure is necessary if there is no option left to offer to the patient. There may be many reasons for this, including a lack of resources or the treatment option in question being the only one that will suit the patient's condition.

4.4.2 Flexibility and compromise with patients

On the other hand, the analysis has also shed light on the fact that some of the HCPs are eliciting patients' needs, preferences and values, in addition to being flexible with them in deliberating the option that suits them best.

For the active ones, I like to know what their preferred choice is first. What is it that they want, we jot it down and what are the choices that I can give to them? Because for these active patients, they have a lot of ideas but we can't take all. Okay, after they gave their ideas, and I gave mine, we'll discuss. If let's say I can accept their idea, we can include it in their management but let's say, if I think the second part is not that suitable for them, and I have a better option, "If you think that you can follow my plan, we merge it. It is not necessarily all of these plans of yours we'll accept. Just the plan A. We might combine plan A and plan B, but we will discard those that we think are not suitable." So, usually they'll try to say, "eh, but I am"... even though they have a lot of ideas but they feel that, it's not really confirmed. So we'll say to them, we can discuss what's the best. (HCP13, diabetes nurse educator, HC)

There are patients who want to do the monitoring every other day, then we'll see which time in course of the day that they want to do it. Is the time suitable with their method, insulin and all? If it is not suitable, we'll change it again. Let's say they want their insulin need to be injected 2 times a day, morning and evening, but they want to check their sugar in the afternoon which is not practical to their condition, so we say, "Okay, it's okay if you want to do that but I would prefer if you do like this", and then we explain to them why. So they'll understand. All of these things depend on the suitability. (HCP7, diabetes nurse educator, HC)

Some of the HCPs in this study understand the importance of being flexible with patients. For these HCPs, even though they believe that the available guidelines are beneficial in terms of helping them in the management of patients with T2DM, it is also important for them to consider their patients, as every patient is a different individual with different preferences and backgrounds, and the guidelines may not suit their particular condition and needs. This is termed by both Charles and colleagues (1997) and Makoul and Clayman (2006) as negotiation and usually occurs when the patients have verbalised a preference for doing something other than the recommended option, thus potentially generating conflict. Usually, the HCPs will negotiate in a bid to find some middle ground between the recommended option and the patient's request. For these HCPs, both their recommended option and the patient's preferred option will be fully explored and they will endeavour to identify something that both sides can work with. Nonetheless, both HCP13 and HCP7 believe that discussion helps them to recognise what patients want at the same time

as maintaining their position as the health expert and that they can still help patients to understand why their preferred option might not be good for them.

However, aside from their intention to ensure that the chosen and planned management can be better carried out by the patients, it can be argued that another reason for HCPs to enter into discussion is to find a better way to convince patients to accept their recommendation, based on the premise that the patients can be persuaded that the recommended option is better than their preferred one. Sandman (2009: p. 238) makes the assertion that *"... if the conflict is resolved or disappears as a result of rational deliberation, this cannot be characterised as a compromise or as not as optimally satisfying the interest of the parties"*. This effort should not be viewed lightly, however, as it is an indication that the HCPs are beginning to open up to the idea of taking patients' opinions into consideration in the decision-making process, to ensure that the planned management will suit patients' individual conditions, needs and values. Brown and colleagues (2002) found the early acknowledgement of a patient's preference by HCPs to be the most useful way of encouraging their involvement in decision-making. This is very similar to the practice by HCP13, as illustrated in her excerpt above. This finding also reflects how the HCPs listen to their patients' needs and concerns, which is vital in therapeutic communication not only from the western perspective, as asserted by Saba colleagues (2006) and Entwistle and colleagues (2008), but also from the Asian perspective in particular (Claramita, Nugraheni, van Dalen, & van der Vleuten 2013).

4.4.2.1 Patients trying different options

In this study, some patients were allowed by their HCPs to try their preferred choice, while other patients were asked to try their HCPs' suggested option, in order to help them identify the option that they were most comfortable with. Giving patients the opportunity to choose their preferred option themselves is a good indication of decision-making being tailored to each patient.

> *Actually about the suggestion by the private doctor, I did ask the doctor here, "Can I try this medication?" He said okay, if I am brave enough to try. Try it for one month, and see whether it will help or not, and if not, I should stop. (PT24, 44-year-old, Malay woman, HC)*

According to PT24, she was allowed by her doctor to try her preferred medication, but the above account also illustrates that the physician was not overly optimistic with regard to its effectiveness over that of the recommended treatment. It seems that the physician was allowing PT24 to try her preferred option as a way of proving to her that it would be neither effective nor suitable, meaning the patient would eventually agree to the recommended option. This is one way in which HCPs can try to convince patients that their recommended treatment method is the best and works as a subtle way of them avoiding any conflicts in their effort *'to right the wrong'* (Shea, 2016: p. e249).

> *...and what I do sometimes is the ones that are 50-50, whether they want to take it or not, I try to bargain with them, "Okay, aunty, I'll give like 2 weeks for you to try first, and if you can't do it, it's fine I'll remove it and we can try again some other time". (HCP5, medical officer, SC)*

In other cases, HCPs tried to bargain so that their patients would agree to try the suggested treatment. By extending an offer for a patient to carry out their own experiment with the suggested treatment, HCP5 hopes that her patients will be persuaded that it is not as bad as they think and will agree to continue with it. Whether allowing patients to try their preferred option or asking them to try the recommended option, it would appear that both approaches have the same objective on the part of the HCPs; that is, to persuade their patients to ultimately provide their implicit agreement for the recommended treatment. Even though persuasion in this context is deemed acceptable by Shaw and Elger (2013), it does deviate from the main objective of the shared decision-making approach, which is to ensure that the most suitable option for each patient is identified and selected. However, in the defence of the HCPs, patients may not be able to correctly identify which option suits them best suit if they are not in a position to try every available alternative. This is

aligned with the assertion by Montori and colleagues (2006) that shared decision-making in T2DM allows patients to try different options due to the chronic nature of the condition.

4.4.3 Section summary

Following on from the previous section of 4.3, where the presentation of options and their related information was seen to be routinely biased, scarce or even non-existent, a similar finding has also been shown for when there was discussion involved in making the decision. There was only limited investigation of patients' preferences, and discussion or negotiation was generally shaped to influence these preferences so that the patients would agree with the HCPs' recommendation. The latter was routinely carried out using persuasion and intimidation, which is akin to the finding by Greenfield, Kaplan, Ware, Yano and Frank (1988) and further supported by Upton and colleagues (2011). These findings highlight the lack of deliberation practice among HCPs in the study context. Nonetheless, most of the HCPs in this study use this technique of persuasion and intimidation as they believe it to be effective in protecting their patients from options that they believe may be harmful to them, while at the same time trying to respect their autonomy.

On the other hand, some of the HCPs aimed to elicit their patients' preferences and engage in a discussion about the 'pro and cons' of each available option so that a middle ground could be found. In some cases, HCPs also suggested that patients then try to change the management so that the best option may be identified to fit each individual patient. Both of these are examples of patients being offered an element of flexibility and are parallel to the recommendation within many of the existing shared decision-making models (Charles et al., 1997; Makoul & Clayman, 2006; Elwyn et al., 2012).

4.5 Final decision

Politi (2013) asserts that shared decision-making does not include an obligation for the final decision to be made equally by patients and HCPs. Street, Makoul, Arora and Epstein (2009), on the other hand, highlight the importance of a mutual agreement by both sides on the decision that is made. In making the final decision, the data from the participants in this study reveal the following three main approaches: 1) HCPs making the final decision; 2) patients and HCPs deciding together, and 3) patients making the final decision.

4.5.1 HCPs making the final decision

The most common situation to have emerged from the data is that the HCPs play a greater role and have more responsibility in making the final decision. Through their personal accounts and from the further analysis, most of the HCP participants are seen to believe in the benefit of involving patients in discussions about their condition, preferences and values, although it is the HCPs who make the final decision and this is then agreed by the patients.

> *So I tell them, "This decision, I can make this decision very easily, but this medicine is going into your body, so yes we have to have the discussion, you and I will discuss the pros and cons, but the final decision, you have to allow that to be mine… You have to trust that I'm giving you this medicine to help you." Because if I left the decision to them, they would say, "no, I don't want the medicine". They don't want any medicine. They want their diabetes to be magically managed. I guess it makes sense, nobody wants to take medication. So I explain that to them. I explain, "This is the discussion because you need to be aware and you have to share the decision-making, but you need to understand the final decision should be the doctor's. You know, because if you tell me, "no, I don't want this", I can't just write there, the patient doesn't want this medication. (HCP15, FMS, CC)*

From this account, HCP15, as the FMS, clearly demonstrated her perspective on the HCP being the decision maker, recognising that they are the experts in the medical field and not their patients. This was despite her awareness of the benefits of shared decision-making. HCP15 also believes that many patients would never voluntarily

opt for any medication as they ideally want their T2DM to be miraculously cured. This suggests that she most probably lacks trust in a situation where her patients are involved in the decision-making process, believing they would not actively contribute to the selection of what she considered to be the best treatment; this is again despite her recognition of the importance of holding a discussion with her patients as part of the process. This is supported by Saba and colleagues (2006), who mention that trust in shared decision-making is bidirectional.

HCP15 also believes that decision-making is shared with her patients as she encourages discussion in the earlier stages of the process, which differs from the assertion by Politi (2013) regarding shared decision-making. Nevertheless, as the objective of the discussion is mainly to instil a better understanding in patients of their condition and the prescribed treatment, with a view to them being more accepting of and adhering to it, this may lead to a lack of the exploration and consideration of patients' preferences and values that is deemed to be the essential basis for shared decision-making. HCP15 also appeared to detest the idea that she needed to report patients' rejection of her recommendation. Among the cases referred to her were patients that her subordinates were unable to manage; as such, her failure to make the patients agree could be perceived as an inability to fulfil her expected role as an FMS.

> *Patient involvement, well, for me, I always practise shared decision-making for my patients. I do not force patients. To me, I always have an open kind of discussion regarding options for therapy. But the typical patients may feel a bit more comfortable when the doctor decides for them to do next because of their background knowledge and awareness is less. (HCP19, endocrinologist, HC)*

> *So, they come they look at you in a very blank way, you know, you have to push them to get interested, when we are talking about management, they say, "You're the doctor, you decide". The problem is I don't think that we want to make the decision for the patients, the reason we decide because they don't want to make a decision. (HCP15, FMS, CC)*

I don't really mind, as long as they take good care of me. (PT6, 54-year old Malay woman, SC)

On the other hand, some of the HCPs, HCP19 and HCP15 for example, outlined how patients often give them the final decision-making power despite being encouraging to become involved in making a decision. This is comparable to Levinson and colleagues (2005) who revealed that, despite the patients in their study appreciating shared decision-making, half of them preferred for the final decision to be made by HCPs. It is presumed that this preference will be more apparent among Malaysian patients who come from a collectivist and high power distance culture where HCPs are often viewed and respected as people who are wiser, as is apparent in PT6's account. In Malaysia, HCPs are seen as benevolent authority figures in the health and medical fields, and it is common for patients to make every effort to avoid the uncertain consequences of disagreeing with them or requesting other options (Kennedy & Mansor, 2000; Khairullah & Khairullah, 2013). PT6's account is also comparable with a study by Peek and colleagues (2008); here, the study's patients did not mind how the decision was made, including paternalistically, as long as the HCPs took good care of them and provided them with sufficient information.

4.5.2 Deciding together

I believe from the beginning of their diagnosis till the point of continuation of care with them, they're always needed, it's almost necessary that they are involved in the decision-making process of what sort of treatment they are to receive. It is not gonna be a one-sided, or only physician directed decision-making for the patients, cause at the end of the day, the patients are the one who received the care and they would benefit most in treatment or modification which is suitable for them. (HCP17, medical officer, HC)

Some of the HCPs openly stated that they involve the patient in making the decision. HCP17, for example, prefers for the final decision to be made together and she usually tries to find an option on which both parties agree. This aligns with the recommendation by Charles and colleagues (1997) that shared decision-making is a middle ground where there is a high possibility that none of the involved parties'

preferences will be fully satisfied. HCP6's preference for deciding together was due to her belief in the greater benefit that this approach would bring for the patients, which is akin to the findings by Desroches, Lapointe, Deschênes, Gagnon, and Légaré (2011).

> *I think it should be okay, because sometimes we don't understand which medication will suit our condition. But for me, even though the doctor knows about medications but have they ever taken those medications? So, we're the one who takes it and experience the effect. So, the doctor, for example, they may advise us and for us we have to tell what our problem is too. So, from there, maybe they could combine all of the information gathered and try the most suitable one. We'll continue taking the medication if we don't have a problem or side effect from it. If I experience any of it, I might discuss back with them, to see what else that we can do. (PT12, 29-year-old, Malay woman, HC)*

PT12 expressed her preference for a decision to be made together as the input of both patients and HCPs is important to ensure that the best option is chosen. The fact is that it is the patients who have to carry out the management and experience the effect, whether this is positive or negative, and PT12 believes it is crucial for patients' views to be taken into account when determining the treatment. Being involved in making the decision in the first place would mean she also felt more comfortable to share, further discuss and perhaps find a better way if it was felt that the current management was not suitable. Moreau and colleagues (2012) found that the patients in their study viewed shared decision-making as this type of interactive process, whereby most of the young and middle-aged patients preferred for the decision to be made together. The account from PT12 also clearly indicates that she feels responsible for her own management since the decision was made by her and her physician and, due to shared deliberations, she understands that there are also other options if the current agreed management does not work for her. This suggests a strengthening of patients' sense of empowerment through the bidirectional transfer of knowledge and therapeutic alliance between patients and their HCPs (Moreau et al., 2012). Further explanation and discussion on patients' sense of empowerment is presented in the next chapter.

4.5.3 Patients decide

In rare situations, certain HCPs state that they would let patients make the decision after having given them all of the available options and related information, which is termed informed choice or autonomous decision in some of the literature.

> *…we must give them two options, you know. If you want to do the dressing with dermacyn, you also can. The healing process will still take place, but more slowly. So, we will leave her on that, but we will ask them to put a little bit of cream and all, so that the puss from deep inside will come out. (HCP1, staff nurse, SC)*

From the data gathered, this permission is more apparent in non-pharmacological management, with patients usually being able to modify their treatment based on their judgement, preferences and values at different times and conditions throughout their disease process. For this type of management, patients will usually have the opportunity to test and modify the management in order to find the method that suits them best. The account by HCP1 is an example; here, the patient has to attend the clinic at least once every three days for the purpose of diabetic wound dressing, with the method recommended by their HCP incurring an extra cost that would have to be borne by the patient. In this case, the patient has more opportunity to be autonomous and try different options compared to trying out different medications that can only be changed when they meet with the physician, usually at intervals of at least two months. This may also be the reason why the HCPs are more open to their patients being involved in the making of non-pharmacological decisions compared to the more authoritative decisions related to their medication.

> *Because I've tried all oral medication and it caused diarrhoea. So, I wasn't comfortable, as I had to run to the toilet every day. Then, I asked for it (insulin). Actually, at first the doctor seemed reluctant to prescribe me the insulin as I was at the early stage, but then he just gave it to me and since then, I haven't any symptoms like diarrhoea anymore… that's why I asked just now, because, they told me to take it 30 minutes before a meal. But I wasn't told what would happen once I took it. So, I don't know. (PT22, 34-year-old Malay woman, HC)*

Analysis of the data from the patients highlights the HCPs' lack of preference for and practice of autonomous decision-making. However, a few patients did describe experiences of making their own decisions during the encounter. PT22, for example, decided to begin insulin therapy despite it not being the recommendation of her physician. Despite her physician's agreement after she had insisted on it, it appeared that she was not fully informed about her chosen treatment. The patient was then left with the thought of being abandoned by the HCP after she had selected an option other than the recommended one, something which would most probably make her feel uncomfortable with both her involvement in the decision-making process and the option that she had decided upon. This echoes the assertion by Davies and Elwyn (2008) who emphasised the importance of support for patients who may potentially develop a sense of abandonment as they have made their own health decision. As such, these patients usually feel compelled to agree with the recommended treatment in their next consultation and this is just their way of pleasing and gaining reassurance that their HCP will not abandon them, even though they may not truly feel that the option is the best one for them.

4.5.4 Section summary

The examples in this section have provided insight into how the final decision is made in a variety of ways. Nonetheless, the HCPs are the main decision makers for reasons including their lack of trust in their patients' ability and motives, patients' preference for the HCPs to make the decision for them, and patients' lack of understanding and awareness of their right to be involved right up to the end of the decision-making process. It is also explicit in the examples that the decisions that are made paternalistically are those relating to patients' pharmacological modalities. The paternalistic way of making the final decision is predictable as it is parallel with the previous findings that have been presented in the earlier sections of this chapter. Nonetheless, in some instances, the final decision is made via a process of discussion and mutual agreement by patients and HCPs. This happens when both sides realise and accept the contribution of each other, which they believe can facilitate an

improvement in the patient's overall condition. Finally, autonomous decisions in this study took place only rarely.

4.6 Chapter summary

This chapter has explained the current practice of decision-making in the study context from the participants' perspective. The HCPs were found to focus on patients' biomedical and physical status when seeking to identify the patient' problems and throughout the decision-making process. In addition, patient involvement in this phase was often limited to queries posed to them by the HCPs, as not many of the patients would actively share their problems and concerns without first being asked by the HCPs. Consequently, it was common for the patients to feel that the root of their problems was not being fully addressed, which they also perceived was a situation that could be improved through a process of shared decision-making. Nonetheless, it is also shown that interaction between HCPs and patients does take place during the initial phase of decision-making, despite there being a lack of this overall. The patient–HCP interpersonal relationship and communication was found to play an important role from this initial phase since the lack of a prolonged relationship, combined with the language barrier, was identified as hindering the involvement of patients in identifying the problem to be addressed.

Following the identification of the problem to be addressed, the examples given in sections 4.3 and 4.4 demonstrate that the HCPs took different approaches to making the decision. In some cases, the decision was made paternalistically, with limited or no information provided to the patient. However, in most cases, the patients were presented only with the HCPs' recommended choice, with any subsequent information provided and discussed by the HCPs with the aim of persuading the patients to agree and adhere to this option. Other options may or may not be presented based on feedback from the patients. Despite the high likelihood of the best option for patients being the one that is recommended to them since it is made by HCPs based on the established guidelines, the way in which information is presented may lead to other problems as it can potentially hinder a sufficient level of

discussion, which is important in terms of improving patients' understanding and also to address their dissatisfaction and any future non-adherence. In other cases, meanwhile, various options were given to patients, taking into account their preferences and values, and a discussion was held to ensure that they were given sufficient information to enable the best option to be chosen that best suited their needs.

Similarly, based on the descriptions by the participants, it was common for the final decision to be made paternalistically, either with or without an explicit agreement from the patients. This is aligned with their preferences, the belief of HCPs as the experts and the patients' lack of awareness. Some of the participants preferred to try and find a middle ground and decide together as they believed this would yield the most benefits in the future. Occasionally, the patients were described as making their decision with or without sufficient knowledge and support from the HCPs. This led to further consequences for not only their management but also for their future encounters with the HCPs.

In conclusion, as the participants in this study, patients with different levels of involvement in decisions regarding their management have different views about the practice. However, HCPs still play an important role in the decision-making process, whereas patients play a more passive role. This is comparable to the findings of studies conducted all over the world (Bugge et al., 2006; Hajos et al., 2011; Pellerin et al., 2011; J., McDonald et al., 2012). Furthermore, this study finds that patient involvement remains limited in terms of the extent to which HCPs grant patients the opportunity to be involved in making decisions. The next chapter contains a further exploration of the factors associated with patients' understanding of the practice of shared decision-making.

CHAPTER 5: EXPLORING PATIENT INVOLVEMENT IN DECISION-MAKING: BOURDIEUSIAN PERSPECTIVE

5.1 Introduction

Most of the participants' descriptions of their experiences with T2DM treatment and management decisions have at some point featured patient involvement and shared decision-making, as presented and discussed in Chapter 4. Moreover, it can be sensed from the previous chapter that most of the participants employ different approaches of decision-making, ranging from HCP-driven outcomes approach, to patient-driven outcomes. However, HCP-deriven outcomes approach or paternalism remains dominant.

Aligned with symbolic interactionism as the theoretical perspective underpinning this study, perceptions of the practice according to both patients and HCPs were thoroughly explored and found to greatly influence the current practice of patient involvement in decision-making in the study context. Furthermore, as mentioned in Chapter 3, Bourdieu's thinking tools on the concepts of habitus, field, capital and power have been used as an interpretive lens through which to illuminate the factors that shape the participants' understanding and practice of patient involvement in decisions, as presented in Chapter 4. In applying these concepts to the data analysis, this chapter presents patient involvement in decisions as being heavily reliant on patients' and HCPs' past experience and motivation, in addition to their perceptions, values and beliefs in relation not only to their individual characteristics but also to the characteristics of each other and their embodiment of the norms of the healthcare system and culture. In addition, aligned with Bourdieu's work, the discussion of the characteristics of patients and HCPs in this chapter covers not only their sociodemographic characteristics but also their habitus (including the patients' sense of empowerment and embodiment of the sick role, the HCPs' embodiment of their professional roles and their permissive and dismissive characters) and capitals (economic, social and cultural).

5.2 Patients' characteristics, values and beliefs

This section will discuss the findings of further exploration regarding the influence of patients' characteristics, values and beliefs on their involvement in decision-making. These include patients' expertise and contribution, their beliefs and values in the decision and treatment modalities, acceptance of public facilities, and their sense of being good patients.

5.2.1 Patients' expertise and contribution

Chapter 4 highlighted how the treatment decided upon during the encounter was based more on HCPs' technical expertise, with the decision being made by the HCP. It was also demonstrated in 4.5.1 that this occurs not only because the HCPs prefer to make the decision for the patient but also as patients refuse to make it, preferring instead for the HCPs to make it on their behalf. One of the principal factors appearing to give rise to this preference among patients and HCPs is the lack of appreciation and value placed on the lay expertise of patients by both themselves and HCPs.

> *What is the point for me to be clever? I don't have any expertise. You are the doctor, you tell me. (PT2, 61-year-old Indian man, SC)*

PT2 is one of many patients who consider their contribution to be less necessary compared to that of physicians, who are considered to be the experts. Owing to the low value placed by this patient on his experiential knowledge in comparison to the technical knowledge of the HCPs, he prefers to take a passive role in decision-making, anticipating that the physicians will provide the information relevant to the decision. This corresponds to the findings from a study by Protheroe, Brooks, Chew-Graham, Gardner & Rogers (2013), where the patients felt they were not expected to take an active role in making the decision. Instead, they considered it to be the role of their HCPs, as the experts, to tell them what to do and decide what was best for them.

It depends on the doctors too. If she forces me to take Gliclazide, I might stop the insulin injection. But, as she gave me the opportunity to make the decision, so I decided to continue. If there are options given, I'll choose. But, if there is none, I'll not make it. Because they know better, they are wiser. Who are we to compare as I also don't have any medical knowledge? (PT11, 36-year-old, Malay woman, HC)

Contrary to PT2, PT11 wanted to be actively involved in choosing her T2DM management. Again, however, due to her concern about not having the requisite technical knowledge, she had a reservation over whether or not to become involved and made no request to be involved after the opportunity was not presented by the HCPs. This finding is supported by HCP3 in the following account, in addition to the findings of a study by Fraenkel and McGraw (2007). The latter also demonstrated that dependency commonly occurred among the patients in the study when they failed to recognise and understand that their contribution to the discussion on their management decision was based more on the non-medical part and their personal preference, thus leading to their more meaningful involvement in making the decision. The point illustrated in the following account by HCP3 was also outlined by Hartzler and Pratt (2011), namely that this non-medical expertise of the patient is focused on their strategies of coping with the daily health challenges they face, which they develop through their own experiments with their management.

Sometimes there are side effects from the medication, so they don't take the medication. If I pick up on that, I will go and ask the doctor if it can be changed to something else. For example, Metformin, a lot of them have diarrhoea and others, because of that they don't take, but they never tell the doctor. But during these sessions, I'll ask them, and then I'll found out… (HCP3, pharmacist, CC)

However, the sentiment expressed by PT2 and PT11 is shared by most of the patients, in that they fail to acknowledge that their experiential knowledge in dealing with their diabetes management places them on a par with their HCPs in terms of contributing to the discussion on the selection of treatment modalities. Larsson, Sahlsten, Segesten, and Plos (2011) linked this to patients' low self-esteem as they do not consider themselves able to understand their own condition and face

challenges in managing it, therefore leading to their non-involvement. We can add to this the Malaysian culture with its great emphasis on hierarchy. The placing of greater value on the technical knowledge of HCPs bestows on them a higher position in the health and medical field, where power is unequally distributed between the different levels, although some improvement in this has been evident over time (Hofstede, 1980; Ken & Ying, 2013). Consequently, many of the patients believe that their T2DM management should be decided by the HCPs during the consultation and that their participation is limited to what is allowed by their HCPs.

> *I don't know. Maybe they don't have the knowledge or it's easier for them, they just have to follow whatever we told them, "It's okay, you just tell me, and I'll do it". Most of the patients are like that, they don't mind. (HCP7, diabetes nurse educator, HC)*

However, besides a lack of recognition of their own contribution in deciding their diabetes modalities, the reasons for patients' preference to hand the responsibility for making decisions to their HCPs and for not entering into a discussion with them are debatable. As demonstrated in HCP7's account, it can be argued that patients prefer to play a passive role since this requires less effort compared to being an active patient, which was also asserted by Solomon (1948). Diabetic patients need to make considerable effort if they are to remain an active partner in the discussions with their HCPs, reflecting the chronic nature of diabetes as a disease. They have to continuously learn about their condition since most cases of diabetes progress and require concomitant changes in management. Over time, some patients may become tired or frustrated as they perceive no point in becoming involved, as illustrated in the following account by PT2.

> *No. Long time ago. Now I have no time. I have better things to do. (PT2, 61-year-old Indian man, SC)*

> *...I feel it is better if discuss, discuss together. Because like me, I don't really have high knowledge in the medical field so it's better for us to discuss. Listen to their recommendation, let them check our condition. Look at the suitability.*

Because they can evaluate whether I am suit or not with the medication… Because in my opinion, sometimes, certain medication doesn't suit us. Because from my experience, high blood pressure medication, when I took it, my leg swelled. Another one is cholesterol medication, when I took it, my whole body ache… (PT24, 44-year-old, Malay woman, HC)

Nevertheless, PT24 perceives her non-scientific contribution to the making of decisions to be as important as the medical and health expertise of the HCPs. A similar type of appreciation was evident among the patients in a prior study by Fraenkel and McGraw (2007), triggered by the patients' realisation that they would be the ones left to deal with the outcome of the chosen treatment. This realisation was prompted mainly by their experience of managing their health condition and empowered them to take an active role in making decisions. PT24's desire for decisions to take into account the input of both patients and HCPs aligns with the concept of shared decision-making. Further description of patients who believe their input is important in making the decision is presented in 5.2.1.1.

Sometimes, patients are more aware of their ability, their restriction, better than us and they just about to start. We don't target too high, as we don't want the patients to feel disappointed. When they feel disappointed, they will not be able to reduce the weight and later on they don't want to do it anymore. (HCP4, dietitian, SC)

Entwistle and colleagues (2008), meanwhile, emphasised the importance of the value placed by HCPs on the contribution of patients to decision-making in the context of encouraging patient involvement. In their study, some of the HCPs acknowledged the patients' diabetes experience, values and preferences as their expertise. Such HCPs felt that these elements should not be taken lightly in order that the option and goal established would be aligned with the patient's individual condition and also as a means of avoiding frustration, as illustrated by HCP4 in the above account.

Of course, I prefer those who are involved, because the selections might be more practical to them…For me it's important for them to be involved, means that they tell us why they can't do it, what are their restriction, so we can

discuss especially for the obese ones. Why? Are they having trouble at their office? Are their friends offering food? or they are the ones that can't control? What are their problems? Easier for us to discuss and as for me, I'll see the results as they're improving and better. So next time they come, at least they can change 1 thing. As for me, no need for too many changes at one time. (HCP4, dietitian, SC)

HCP4's account above further demonstrates that she, by valuing her patients' expertise, prefers for them to be involved and tends to take into account the information that they share when it comes to identifying the different options that are suited to them and eliciting their preferences when deciding on their management. Due to this, it also appears that HCP4 attempts to set realistic goals, which Baillie (2016) identifies as being more patient-centred goals. This will make the long-term achievement of the goals by the patients both more likely and more sustainable.

However, many of the HCPs in this study do not share this opinion with regard to the importance of patients' non-technical expertise in deciding their management.

No, no. They're just being given the opportunity to listen and accept only. There's no way that the information goes to us. They are not allowed to tell the HCP. Maybe because we think that we know better than the patients. (HCP16, dietitian, HC)

HCP16's account above conveys the value and practice found more commonly in this study, whereby HCPs place only limited value on the experiential knowledge of patients. Consequently, the HCPs effectively put a limit on the amount of patient involvement they allow in decision-making.

They actually can decide, it just that they don't want to. Maybe they don't know as they are not the experts. So, they are not aware that they can actually decide. Medication, for example, what kind of medications that are not suitable and everything. Actually, they can be involved but they don't have the knowledge, so it's a little bit hard for them to be involved in the deciding. Their decision is only yes or no. Not the kind decision that "can I

choose this medication, doctor?" Not like that, just yes and no. In terms of medication, we are the ones who manage. (HCP11, medical officer, CC)

Furthermore, other HCPs shared the same view as HCP11, that their patients refuse to be involved in the decision-making process due to a lack of the higher cognitive ability needed to be involved in a more complex discussion about their diabetes. This usually resulted in only the most basic level of patient involvement in the selection of their management. Patient responses to queries from HCPs tend to be limited only to agreement or disagreement with the HCPs' recommendation, thus frequently preventing them from becoming involved in further information exchange in a manner that is more empowered and useful. This highlights HCPs' view of patients' technical knowledge as being their expertise, instead of their experiential knowledge.

Consequently, owing to HCP11's perception that patients do not have the requisite technical knowledge, it is also perceived that they do not have the capability to be effectively involved in making the decision. Therefore, the HCP prefers to be the decision maker, especially with regard to decisions on pharmacological modalities. This is despite HCP11's claim that she encourages patient involvement. However, Wagner (2000), together with Kambhampati, Ashvetiya, Stone, Blumenthal and Martin (2016), argued that this preference of HCPs may limit the acquisition by patients of the information and skills they need to help build their confidence and cognitive ability to contribute to making the decision, thus resulting in a vicious circle of a lack of patient involvement in decision-making and limited technical knowledge about their T2DM.

In addition, the accounts by PT11, HCP4, HCP16 and HCP11 strongly illustrate that HCPs' appreciation of patients' expertise is vital, with it being evident that it is the HCPs who continue to steer the decision-making process at these study sites, including the extent to which the patient's contribution is taken into account. According to Dubbin and colleagues (2013), patients' appreciation of their own contribution, particularly their non-technical expertise, depends on the value

accorded to it by their HCPs. This will further shape patients' involvement in decisions during their future encounters with HCPs.

5.2.1.1 Empowered patients

The discussion on patients' expertise in the previous subsection of 5.2.1 leads to yet another important theme, that of patient empowerment. Patients' sense of empowerment has been recognised as one of the important elements in shaping their attitude and practice with regard to their involvement in choosing their own management or treatment.

> *Like just now, I told her everything… I wrote everything including what I eat. Sometimes, some people are afraid to reveal about their diet, as their sugar is high. I just admit what I eat because it's like a self-reminder to me. I'll note the food that I take if my sugar is high, so next time I will not take that food again. Coconut rice, for example, we know that not only does the rice contain sugar, but also the sambal. So, if I'm craving it, I'll just take some of the rice and some of the sambal only… Because I'm worried. I want to share I went through it already. It can happen very fast. I think I've done it wrongly. (PT11, 36-year-old Malay woman, HC)*

With regard to the few patients found to be taking charge of their diabetes management and playing an active role in managing their condition, they shared their practice and concern with their HCPs. This was combined with an intention to further educate and take better care of themselves. Taking PT11 as an example, her active involvement during the encounter was prompted mainly by the concern that her T2DM would worsen without good management. This concern was based on her past experience of having an uncontrolled glycaemic level due to her incorrect self-management. Her effort to share information with her HCPs as she wanted to improve her diet served as a good indicator that she is empowered since she is evaluating her diet and examining it in the context of relating her food intake to her blood sugar level. This account is consistent with the definition of empowerment by Funnell and colleagues (1991), who defined empowerment as a patient's own ability to have a better understanding of their diabetes condition with the support of HCPs.

We can also see that PT11 had no concern with regard to informing her HCPs that she had consumed foods that were considered unhealthy as she needed their help to better plan her diet in the future. This supports the assertion by Weiss (2006) that empowered patients will usually be more open with their HCPs as they value their expertise in helping them to identify what is best for them as a way of helping them adjust their current diabetes self-management. This can be seen in the below account by PT8, where the patient is empowered and actively puts forward his preferences as a result of his experience of dealing with T2DM over the years. These findings correspond with the concept of empowerment that Lather (1991: p. 4) defines as *"... a process one undertakes for oneself; it is not something done 'to' or 'for' someone"*.

> *No, I don't want. I will tell. Previously, I just followed. My panel doctor prescribed me with the best medication, when I was still working, Avandia. If you remember, if you Google Avandia, it was claimed to be the best for diabetes, to cure diabetes. But, when it was confirmed to cause kidney problem, so when I heard that, I was like, "I was one of the guinea pigs, I became the victim". (PT8, 61-year-old, Malay man, HC)*

On the other hand, the above account by PT8 illuminates a different aspect of the trust in the patient–HCP relationship. The existing literature commonly describes a high-trust patient–HCP relationship to be one of the cardinal elements of patient empowerment (Mechanic, 1996; Nygårdh, Malm, Wikby, & Ahlström, 2012). Instead, PT8 became more empowered only after his health status had worsened, which resulted from the 'bad' decision made by his previous physician. He thus felt cheated as he put his full trust in the HCPs to decide for him. He perceived that he had to take an active role so that the HCPs would not take advantage of him by easily making a decision and not being careful and thorough about it. Aligned with symbolic interactionism, which addresses the fact that meanings can change over time (Blumer, 1969), this patient's perception, altered by his bad experience, empowered him to both share his problem with his physician so that it could be properly managed and to alert his HCPs to matters that were concerning him. This patient had also begun to seek information, although he did not always share this

with his HCPs. In addition, the previous account from PT11 demonstrates how she used the individualised information gathered from her enquires when carrying out her self-management. These findings support the existing literature in which it is suggested that patients' sense of empowerment has a positive impact on their adherence to their diabetes management and improves their overall well-being (Sigurdardottir & Jonsdottir, 2008; Hernandez-Tejada et al., 2012).

> *Haa, they don't want to add their medication. Even the doctor at the primary clinic said, "I'm having a headache. Patients themselves told me not to simply add any medication". Patients said they know their body. So, they want to control their diet first. That's why we have a high number of references to a dietitian. Patients asked the doctors to refer them to us. It is the current trend. Previously, they were more like, "no need for this". This is the comparison with 5 years ago, there were a lot of defaulters, we know. As for now, the number of defaulted cases is decreasing. (HCP16, dietitian, HC)*

> *...If they want to add my medications I will ask. I don't want to take these medications as people say it can cause kidney problem, right? I'm afraid that I've taken too many medications, especially these diabetes medications. (PT18, 55-year-old Malay woman, CC)*

Despite the fact that there seemed to be a lack of patients in this study with a good sense of self-empowerment, the account by HCP16 indicates that their number is increasing. As such, more and more patients are expressing concern regarding the amount of medication that they have to take as they believe it gives rise to long-term adverse effects, as also featured in PT18's account. This in turn leads to them rejecting the idea of a higher dosage or of adding to their existing medication. Instead, they raise the possibility of their T2DM being better controlled through dietary modification and request further support to improve their diet. As a dietitian, HCP16 welcomes these requests despite the potential difficulty they may cause for physicians. These active and empowered patients no longer simply agree to abide by their physicians' instructions or suggestions since they consider that their experience and how they feel their bodies have reacted to their current and previous diabetic management must be taken into account when making any decision on new changes to their treatment and management. They have been driven to voice their preference

based on the fact that they are the ones that have to be responsible and bear the consequences if the chosen management does not suit their overall needs. HCP16's account also demonstrates that patients are more likely to adhere to management that is in line with their preferences as she mentions that more and more patients attend appointments with a dietitian compared to a higher number of non-attendees in the past.

Nonetheless, it can be sensed from HCP16's account that some physicians would not especially welcome patients' determination to stand by their preference and not merely agree with the physician's recommendation; indeed, further exploration indicates that this is despite their openness to the idea of patient empowerment, as asserted in the below account by HCP17.

> *He asked me to reduce my weight. I told him, "Doctor, I'm on a lot of psychiatric drugs, that's why I gain weight". "Don't give excuses." He said that to me. I was shocked. I was really shocked. "Don't give excuses, madam." He shouldn't say that, right? So rough. "Don't give excuses, madam." Steroid, right. You know what the effects are. Weight gain is for sure. What can I do? I have to take the medication to live, to survive. I have to go to work, raise my children. (PT22, 34-year-old Malay woman, HC)*

However, it appears that these empowered patients' efforts to be involved in decisions are routinely being challenged by their HCPs. Similar to the findings by Frosch, May, Rendle, Tietbohl and Elwyn (2012), PT22's account illustrates her difficulty in being an empowered patient and in being involved in the discussion about her management. In addition, her physician adopted a narrow focus on only her diabetic status, which may be considered normal in diabetes management in Malaysia. PT22 gave a reason for her weight gain which was then questioned and eventually deemed by the HCP to be an excuse to justify her non-adherence to her T2DM management. This is comparable with a study by Snow and colleagues (2013) in which it was found that some HCPs were not very comfortable having patients who were confident in being involved in their own disease management, aside from the lack of trust that they had in their patients, as mentioned previously in Chapter 4.

You don't get a patient that comes and say, "hey, you forgot to refer me for my eye check-up. When did you last see my feet?" No. So, if they know better that they should be having their eye check-up, that the doctor hasn't ordered it, that they haven't had their ECG for 4 to 5 years, so maybe the level of awareness, knowledge of the patients… (HCP19, endocrinologist, HC)

Nevertheless, a lack of patients' sense of empowerment was evident in most of the interviews, and in most of the accounts it is possible to relate this to the patients' level of technical knowledge in the first place. HCP19, for example, stated that she had not met any patients who were sufficiently knowledgeable and empowered to ask her about any related medical procedures that they believed they needed based on their prior knowledge of diabetes and awareness.

This is the way Malaysians are brought up, from young. We do, you follow, we do, you follow. Nobody is taught to learn, to understand. We are so into the textbook and read, which is going on, even now. So, these are the youngsters who will grow up as a very ignorant adult. So, they want to continue asking people do for them, instead of thinking themselves and taking responsibility. (HCP15, FMS, CC)

Our education system could be a factor where everybody is waiting for help, waiting for education and the way that the education is transmitted to us is always one direction, it's never two-directional. They are waiting for help. They are not empowered, "doctor, you tell me what to do". (HCP17, medical officer, HC)

Another important issue mentioned by some of the participants, especially the HCPs, is how patients' sense of empowerment, preferences and characteristics in managing their T2DM are shaped by Malaysian culture and its interrelated social and education system. The Malaysian education system can be described as one that relies on a conventional teacher-centred approach and where there is a mostly one-directional transfer of knowledge. In this type of system, information and instruction are usually conveyed by the teachers, with the students listening passively, following the instruction and making occasional enquiries during the learning session. Furthermore, compared with western students, Malaysian students rarely question or argue with

their teachers despite them having disagreements or when teachers make errors as, culturally, teachers must be revered at all times. Similar to the style of education in most other Asian countries, Malaysian students are required to memorise the content of lessons due to the system's focus on examinations, with less emphasis placed on them developing a deeper understanding and less innovation in terms of how the lesson relates to real-life situations (W. K. Lim, 2010a, 2010b). Despite the fact that the Malaysian education system is continuously progressing and teachers are more open to the idea of it being bidirectional and making the effort to ask their students questions, it has been found that these questions are typically not sufficiently challenging to encourage critical thinking on the part of students (Yin Peen & Yusof Arshad, 2014).

The above accounts by HCP15 and HCP17 indicate that the Malaysian education system is capable of exerting a great impact on patients' behaviour during their patient–HCP encounters. This corresponds with Bourdieu's (1990) assertion that educational experience is one of the elements that substantially structures the habitus and practice of the social agent. The educational system in Malaysia has in effect moulded them to be ignorant, passive, dependent, excessively receptive and unquestioning, which in turn can be viewed as being closely linked to their lack of self-empowerment. When the patients carry this passivity into the management of their health, it may lead to them feeling sicker since they have been treated only clinically and physically and not as a whole being (P. W. Chen, 2009). Nevertheless, patients' lack of awareness in this regard, due to them being accustomed to it, results in them not applying their efforts to acquire a deeper understanding with regard to either their diabetes or its management and treatment, thereby posing a significant barrier to them becoming involved in the decision-making process.

5.2.2 Patients' belief and values in the decision and treatment modalities

Another apparent issue found to influence patient involvement in decisions involves their belief with regard to the seriousness of the problem. Some of the patients were

not interested in discussing their concerns and self-management if they felt there was nothing wrong with them, even if they had a problem with their current management.

> *I have 12, 8 for diabetes and 4 for high blood pressure. So I take 2…3….(counting the pills), I only take 4 for diabetes and left the other 4 because my friends said that I mustn't take too much, it will ruin by kidney, so I follow them. So, I take 4 of diabetic medication and 3 of high blood pressure medication. I don't take the other 5….No, I never tell anyone. The doctors will get angry if I don't want to take, they are fierce. But last time I checked my sugar, on the 21st it was good, only 6. On the 22nd, I ate a lot of variety of food, so it increased. When I checked it was 15. I ate mango, paratha, fried noodle, fried rice and iced tea. That's why it increased. In 1 day it increased, from 1 to 7. In just 1 night, I ate a lot and it increased to 7. But it can be reduced very fast. It can be reduced to 5.7 if I control a bit in 2 days. (PT21, 66-year-old, Malay man, CC)*

> *I will wait and see. I'll see the changes, if it is needed for me to tell them, I will tell. If not, I will just stop…I have taken this nerve medication for so long, I can say that I've tried everything from A to Z, but no changes. (PT8, 61-year-old, Malay man, HC)*

PT21 disclosed how he did not adhere to his abundant medication based on a concern about adverse effects. However, the patient shared neither his decision to skip the medication nor his concern, which was founded on information obtained from his friends, with his HCPs. This came despite an increase in his glycaemic level and his prior acceptance of his increased range and dosage of medication. The patient did not perceive any of these things to be worthy of disclosure as they were not serious matters and could be managed easily without being shared with his HCPs. This action can be seen in parallel to prior research that has cited the seriousness perceived by patients and the threat of the problem as important determinants in whether or not a patient takes action; in this context, this means whether or not they become actively involved in discussing their diabetes management decision (Stein, Fox, Murata, & Morisky, 1992; Bishop, Baker, Boyle, & MacKinnon, 2014).

On the other hand, based on his nine years of dealing with HCPs in managing his T2DM, PT21 had come to anticipate a negative response from physicians when dealing with the sharing of his practices (especially with regard to the undesired ones), which may have been a further reason for him to avoid sharing this concern and practice (Rosenstock, 1974). The construction of patients' anticipation regarding their HCPs' response based on past experience is aligned with Bourdieu's (1990) description of habitus. Consequently, it is often the case in this present study that the patients endeavour to resolve their own problems to the maximum extent possible, without discussing them with their HCPs, as demonstrated in the above account by PT21.

Besides, as shown in the above account from PT8, these patients shared information based on a consideration of how their body reacted to the medication. They will only share and consult with their HCPs once the matter is 'out of their hands' and they require action in the form of an HCP intervention. This action that entails selecting the kind of information to put forward during their encounter with HCPs, as shown by PT21 and PT8, is also considered by Bachrach and Baratz (1970) as patients' way of exerting covert power.

Despite T2DM involving patient self-management since most of its related decisions and management are carried out at home, any situation in which patients are not in possession of sufficient knowledge may result in mismanagement on their part. This is evident in PT21's admission that he has covertly modified and reduced the dosage of his medication in an effort to address his concern regarding the greater negative effects that he may develop due to his multiple pharmacological prescriptions, in contrast to discussing the matter. This may also be the reason for his inconsistent glycaemic reading with his HCPs. This can commonly lead to mismanagement by HCPs and to a dissipation of resources as a patient's medication dosage will be perpetually increased in a bid to improve their glycaemic level.

Some, you have to force them to start insulin, because they'll always tell you that they don't want, don't want until their HbA1c more than 10%. From 8-7, maybe they'll just need Insulatard. But if they keep telling you, "I don't want...I don't want" until HbA1c 13, 14, 16. We force them to start… If not, they'll be getting complications or maybe their eyes start to have a problem, and the HbA1c more than 10, the doctors have to start insulin also or the HbA1c more than 8, the doctors have to start also because it can cause cataract and other things. So, if we follow patients, none of them are willing to start injection, actually. Unless they're educated, they know what is insulin, that one is a different thing. So 50-50. I can't say we can make together, but sometimes we can ask patients' opinion. (HC9, pharmacist, CC)

However, the above account by HCP9 provides a different perspective on the relationship between the seriousness of the problems and patient involvement in decision-making. According to HCP9, the bigger a patient's problem, the less chance there is of them being involved in making the decision. This pharmacist prefers to make decisions herself out of concern regarding patients with serious and difficult problems developing complications. This is also due to her experience of dealing with these kinds of patients, in that she believes they will become worse yet will also never agree with the HCP's recommended option, especially with regard to the initiation of insulin. This may also indicate that HCP9 lacks trust in her patients' ability to make the right decision, which was also discussed by Miller (2007). Thus, it can be argued that most patients' practice of not sharing their concerns, combined with their lack of ability to identify the information considered relevant to be shared, may lead to a worsening of their condition. In such an event, the likelihood of them becoming actively involved in making a decision becomes even slimmer as their HCP may not permit them to do so (S. N. Whitney & McCullough, 2007).

5.2.3 Patients' acceptance of public facilities

The other matter that emerges concerning patient involvement in decision-making is their sense of acceptance of the services provided at the study sites, which are public health facilities. This refers to how patients believe they have to agree with and not question the services they receive based on the fact that they pay only small amounts of money at these facilities.

When I was working, I got my medication from the private, I could ask for something more. RM1000-RM2000, they can give me, but when you come to the government hospital, they say, "look, I don't have any other thing, this is what is available, what I can give to you?" They give, I'll take. Our treatment method is not right. But if you are the type who doesn't have the capability to buy, go and see the government doctor, they'll give the best treatment. Because the treatment is good, but not the medication, government doctors do not have it. It's quite expensive. If you're not rich and just average, forget about it, government servant and all that. It is for the rich so, I'll just go on with it. The medications are there, but it's for the rich and famous. (PT17, 58-year-old Indian man, CC)

PT17, who no longer has the financial means to access what he perceives to be a better service at private facilities, believes he is obliged to accept the HCP's recommendation. This belief will serve to not only limit patients' involvement in making the final decision but will also limit their desire to enquire about related information or other available options, as was evidenced in a study by Fraenkel and McGraw (2007). Similar to the findings of this present study, the participants in Fraenkel and McGraw's study also did not believe they had any right to be involved in selecting their treatment due to the fact they did not have to pay for it.

Actually, there's a difference between private and government [facilities]. I know that I can't afford to go to the private. So, whatever they give me at the government, I have to accept as I don't have a lot of money to spend. We only have to pay for registration, which is so much less than in private. As you know, currently, health, education and everything has become so expensive. I don't have insurance to cover my medical expenses. So now, when I'm here at the government hospital, I have to accept it. I'm lucky as I was referred here, where they have all the facilities. If, let's say, I go to the hospital near my hometown, the facilities will most probably not be as complete as what they have here. Here, if you need a CT scan, they will do it immediately. As for other hospitals, they have to wait for an appointment to do it and you have to go there to do it, which might far from their home. But, here, we have to come 2 to 3 weeks before our appointment for a blood test, as compared to the private, where we can go immediately or only have to wait half an hour for the results. But we understand. They have a lot of patients here and we only pay a small amount of money. Even the medication is subsidised by the government, so we understand the quality of the medication. (PT11, 36-year-old Malay woman, HC)

PT11 shared the same value as PT17 in 4.5.1 in the previous chapter when she mentioned that she accepted the recommended management since she did not consider there to be any other option available at the public facility aside from the one being recommended or prescribed by the HCPs. Despite her understanding of the limited options available at these facilities, PT11 implied a sense of lacking power when she said *"I don't have any insurance to cover my medical expenses. So now, when I'm here at the government hospital, I have to accept it"*, pointing to a sense of powerlessness. She expressed her lack of control over the decisions made at the public facility in comparison to those made at a private facility, which she may perceive as being able to offer her better options despite the fact that these would cost more. It seems plausible to relate this sense of powerlessness to her inability to spend more on her medical expenses. This is in accordance with the findings of a study by E. S. Rogers and colleagues (1997), also supported by Bourdieu (1977), in which patients' economic background was found to be closely related to their sense of having power.

> *Here, it's quite slow. They check the sugar (level) after 4 months and if we suddenly have a problem, we don't know how to ask. We can't call them, as we don't know them. Don't know at all, right. For this hospital, I only use their insulin. The rest of the medication, I get from outside. (PT24, 44-year-old Malay woman, HC)*

The relationship between patients' earning potential and their sense of power is further described by PT24. Assuming that PT24 is able to allocate more money to her medical expenses, she went for her preferred option that she obtained from outside the public facility, believing she was being offered a better quality of service and more treatment options. This indicates that she perceived herself as having greater control over her decision compared to PT11, who did not have the capacity not only to access treatment apart from that provided in public facilities but also to be involved in choosing her T2DM treatment. PT24's possession of economic capital clearly affords her greater opportunity to assess healthcare services, in addition to the power to be involved in decisions and to opt for her preferred T2DM management.

The above accounts further highlight the health inequalities among patients. Baum (1998), together with Lynch, Due, Muntaner, & Davey Smith (2000), discussed the shifting causes of health inequalities since the late 1990s and early 2000s, from economic to psychological factors. This recent focus on patients' social and cultural capital may demonstrate a lack of appreciation of the power of economic capital in terms of its contribution to health disparities. Despite this, the health inequalities between the patients in this study were found to be linked to their economic status. This is especially the case in countries in which the healthcare system consists of both public and private services. This includes Malaysia, in which private healthcare is more accessible to people in the higher socio-economic groups (Hassan, 2007; Collyer, 2015).

> *Like just now, actually I'm supposed to be with a specialist, then they put me with the "normal" doctor. "Doc, no offence, I have to see my specialist because she has my records." Then they checked and said that she's seeing the HIV patients today, that's why I can't see her. See, because I asked, what if I didn't? I told her, "doctor, please don't get angry, the specialist has my record and I'm comfortable [with her]". She said, "Can I give you another appointment?" Because I asked and she explained. (PT17, 58-year-old Indian man, CC)*

Nevertheless, there were some patients who felt empowered despite them attending a public facility. PT17 argued that it was important for him to verbalise his preference to be treated by an FMS, believing this still gave him a chance to see her compared to if he did not ask at all. Even though he had to make a compromise in the form of accepting an alternative appointment, his request to see his usual doctor was fulfilled. This scenario serves as a good indication that despite the limited resources available at public facilities, they still attempt to support and fulfil their patients' preferred options so long as the patients put them forward. As such, this renders patient empowerment even more important in the context of public facilities, as all of the available options may not be readily presented to them.

5.2.3.1 Cheap to be sick

Nonetheless, a concern was raised by the HCPs regarding patients' passivity during decision-making based on the perception that it is cheap for them to be sick and obtain treatment from public health facilities.

> *…you know, sometimes when you provide for everything, sometimes it's taken for granted. "I actually come, I waited for so long, so as long as I get my medication it's okay." Whatever we discuss may go in and out, in and out, in and out, in and out. "But I just want my medication"… They hardly pay anything actually for their medication. It's sad, I think the healthcare system may be, to some extent, it's my personal opinion, has promoted to the public who are unaware of healthcare cost. And if you don't know healthcare cost, then you don't prioritise health as healthcare is so cheap and it's quite cheap to be sick. (HCP19, endocrinologist, HC)*

Further exploration of the nominal cost charged to patients in return for access to the public healthcare system shows that their lack of involvement during encounters and discussion about their health decision is not merely due to their acceptance of the limited resources in the public healthcare facilities (as previously explained in this subsection) but is also due to the lack of value that they place on the service they receive. This is apparent in the above account by HCP19 in which she described her encounter with these passive patients whose only concern during their appointment is about receiving medication. It can also be sensed from HCP19's account that the patients' lack of involvement and non-adherence stems not only from the fact that they do not have to pay much for the management of their current health problem but that they also have the perception that it would not cost them much if their condition were to worsen or if they were to develop complications.

> *…They only pay RM1 to see the doctor and all are free until they see their doctor next time. A lot of patients return Metformin, actually. I don't know. Maybe they have follow-up at other places. So, they collect all of their medicine and we can't use it. Same with Insulin we have to dispose it, because we don't know how the patients keep it... (HCP3, pharmacist, SC)*

Similar to HCP19's assertion, HCP3 also spoke of multiple instances of patients returning the medication they should have been taking. According to the guidelines, these medications are not supposed to be used for other patients and thus need to be disposed of (Pharmaceutical Services Programme MOH Malaysia, 2016; WHO, 2011). This can be detrimental as it can lead to an unnecessary wastage of medical resources that might otherwise have been avoided if the prescription had been developed through a process of active discussion between patients and HCPs. However, as asserted by HCP19, not many patients are aware of the increased cost of medical services and supplies. This is because they are not directly bearing the cost, with this instead being met by the government (Thomas et al., 2011).

> *...I have a lot of medication. But I'll take whatever they give. I'll look at the effects as I'm already afraid. Because I knew that if we take so too many medications, it will affect our kidney, so I try to not take too much of it. So, if they give, the ones that they prescribed, I'll take it first, then I'll stop. (PT8, 61-year-old, Malay man, HC)*

> *...But I didn't tell her I didn't take five of my medication. (PT21, 66-year-old Malay male, CC)*

In examining this matter based on the patient data, the above account from PT8 seems to support the concerns raised by HCP19 and HCP3. In receiving the prescription for his medication, PT8 tended to agree with all of the medications suggested for him prior to subsequently considering, outside the consultation time, whether or not to continue taking them. In addition, as is the case in the above account from PT21, some of the patients did not share their self-discontinuation or non-compliance with their medication with their HCPs, thus contributing to a waste of resources.

5.2.4 Being a good patient

Throughout the data, it appears that the patients routinely elected not to share their disagreement with or non-adherence to the recommended or prescribed management with their HCPs.

> *It's hard to say, because we just listen, okay, it's increased. They add, add and add. But we will not add, no. We can't just say, "I eat a lot". We can't say that. If we say that the doctor will respond, "Your sugar has increased, why you didn't control". So, we will be like, "okay, okay". I couldn't say anything else. I just accept it. But, let say I think I eat less, those that they add, I will not take. (PT16, 57-year-old Chinese man, CC)*

> *They give us medication and we take it, but I didn't tell them that I don't take all of it. They might get mad if I tell them. But my friend said, "if you take a lot of medication, it might damage your kidney, it might rupture". But when I asked the doctor just now, she said, "No, it's not. Don't listen to others. Don't listen when they said that medication will damage the kidney as it has to work harder to crush the medication". (PT21, 66-year-old Malay male, CC)*

> *It's like they fight back, right. We have to stand with our way too. We also have to fight on what best for them.' (HCP14, medical assistant (diabetes educator), HC)*

> *Maybe the patients become a little bit more passive, they do it for the doctor's sake. Maybe, they want to please their doctor. Some doctors are very strict, so they do it because they want to make sure when they come to the check-up everything is good, so the doctor will be happy. They didn't realise it's about them actually being having the good outcome. It's not actually to please the doctor but actually, it's for themselves. (HCP19, endocrinologist, HC)*

In the case of PT21, despite him expressing his concern to his physician about the side effects of his oral hypoglycaemic agents, he shared neither his reluctance to proceed with the recommended option nor his non-adherence. It could be argued that, based on the authoritative style of feedback that he received following his prior sharing, which is apparent in the account by HCP14, who describes patients as not

agreeing and as fighting back, this patient chose not to share his concern further, which resulted in his current intention of not adhering to his medication. The patient may not want to irritate his physician, as also demonstrated in HCP19's account, which may then further upset the patient–HCP relationship or lead to abandonment by the HCPs, as presented in 4.5.3. As such, the patients concerned with this matter are commonly more comfortable agreeing with their HCP and would prefer to remain passive during their encounter in order to not be viewed as a 'difficult' or stubborn patient. Frosch and colleagues (2012: p. 1032) reported a similar practice among patients in the US, which they describe as *'conforming to socially sanctioned roles'*. However, as seen in the account by PT16, patients tend to only play this subservient role during the patient–HCP encounter as it is common for them to have no intention of carrying out the prescribed or advised management as they do not consider it to suit their needs, thereby ultimately leading to their non-adherence.

> *Sometimes they think that when they meet with the dietitian, we would not check their dextrostic, so they drink milk tea before they came. That's why when they come to me most of their sugar level is high, because they already know that the doctor will check their sugar and if it's high, the doctor will be angry. So they'll fast or take any herbal medicine. But when they come to see me, they'll be like, "I rarely drink milk tea, but I drank it today as I'm very happy that I can go out this afternoon. Usually, I just stay at home and I don't drink such drinks. I thought that you'll not check my sugar so that's why I drank milk tea and ate paratha". That's why their sugar reached 20. (HCP10, dietitian, CC)*

> *...like previously I went to the clinic, "Don't you love your eyes? Do you want to go blind?" They should've said, "You may lose your eyesight if you are not taking care of your eyes". They have to find ways to deliver the information. Same like elderly, long time ago, when my mom was about to go to the clinic in the certain months, she started to fast, to control her diet. The results were around 6. She'll bring her grandchild's urine for testing. Then, when the doctors reviewed the results, they were happy, no medication was required. The doctors were also happy as their patient was good, her sugar was 6. (PT8, 61-year-old, Malay man, HC)*

Additionally, in this study, the matter seems to be more worrying since a majority of the HCPs tend to display their discomfort to these patients, with most of them

becoming firmer and more paternalistic towards those whom they perceive to be difficult, stubborn or non-adherent, as seen in PT8's account above. This will be discussed further in section 5.3. This account also serves as strong evidence of the negative effect of poor communication skills by the HCPs in addressing patients' concerns, which in this case impeded PT8's intention to share and discuss his concern despite him claiming that he was not intimidated by HCPs.

This is because, in some instances, instead of being compliant with their HCPs, the accounts in this section demonstrate that the patients make an effort to appear as a 'good' patient. In addition to the non-sharing of their disagreement with the recommended management as seen from PT16 and PT21, the accounts from HCP10 and PT8 highlight how they also attempt to do things which they believe will conceal the effects of their non-adherence, especially with regard to their glycaemic level. Such measures include fasting, taking traditional medicine and, to some extent, cheating in their urine test. Patients usually resort to these types of measures in the hope of conveying the impression that they are managing their T2DM well in the eyes of their HCPs, thereby avoiding any further problems in the form of being questioned by the HCPs or an intensification of their diabetes management. It may also indicate that the patients are attempting to control the course of their session with their HCPs and thus using their covert power to prevent conflicts with their HCPs (Bachrach & Baratz, 1970). The account by HCP10 also suggests that the HCPs are starting to become aware of patients' efforts to hide the outcome of their non-adherence.

Nonetheless, patients' wariness of their non-adherence being resented by HCPs is understandable and was addressed by Parsons (1951b) in his book *The Social System*. Here, a situation was described in which patients who fail to conform to their sanctioned roles will face the possibility of social exclusion by their HCPs. Thus, it is common for the patient, as the person who seeks help, to be more subservient to whomever he/she is seeking the help from, which in this case is the HCPs, as asserted in the sick role theory (Parsons, 1951a). Consequently, similar to findings by

Frosch and colleagues (2012), there were patients who were apologetic about taking up their HCPs' time as they discussed their challenges in managing their T2DM, as illustrated below:

> *Few of them actually when you spend more time, I mean you spend more time because the glycaemic control is not good and the control is not in the target, but they actually appreciated that. They will actually look at that like a scenario where you have a lot of patients outside but you still have time to talk to me and make my diabetes control better. Things like that. So, they mentioned that there were few patients that mentioned that, "I'm sorry, that you have to spend more time for me". (HCP18, endocrinologist, HC)*

5.2.5 Section summary

In summary, it is apparent in this section that a patient's characteristics as the social agent of the decision-making heavily influence their involvement in making the decision. These factors include the value that both patients and HCPs place on the patients' experience as their expertise, the patients' own sense of empowerment, patients' belief in the importance of their involvement, the value that patients put on the service they receive from the public health facilities, and their expected role. These give rise to the various practices of patient involvement in the decision and also to the power dynamic between patients and HCPs. It can be concluded from the findings presented in this section that the patients had only limited involvement in decisions and that power was asymmetric since it is the HCPs who determine the extent of the patients' involvement in the clinical encounters. Consequently, it was common for patients to exercise their power outside the clinical encounter.

5.3 HCPs' characteristics, values, beliefs and practice

Similar to patients, the analysis has also shown that HCPs' characteristics, values, beliefs and practice influence the overall experience of patient involvement in decision-making, as presented in Chapter 4. These matters are discussed in this section by dividing HCPs into the two categories of dismissive and permissive. From the exploration, dismissive HCPs are often associated with a lack of patient involvement in decision-making as they tend to equate this approach with patients'

agreement with and adherence to the recommended option, a belief in the superiority of their recommended options and their paternalistic style of communicating with patients. These dismissive HCPs found to be paternalistic in making the decision, which as presented in Chapter 4 as giving instruction rather than options and recommendation, sharing lack of information and options, persuading patients to agree, using intimidating messages and making decision for patients.

Permissive HCPs, in contrast, hold positive views and beliefs about their patients' characteristics, in addition to displaying empathy and compassion towards their patients that typically manifest in their facilitative behaviours and communication style, which ultimately facilitate patient involvement in decision-making. Permissive HCPs tend to give options and recommendations, encourage information sharing, deliberation and compromising, and make decision with their patient or give their patients the opportunity to make decision, as presented in Chapter 4. Finally, this section highlights the difference in engagement between patients and their physicians compared to their non-physician HCPs.

5.3.1 Dismissive HCPs

5.3.1.1 HCPs' conceptualisation of patient involvement in decision-making; patients' agreement and adherence to the recommended treatment

Based on the findings discussed in Chapter 4, the general aim of information sharing and discussion about the decision by the HCPs is to secure the agreement and adherence of patients to the option that the HCPs consider to be the best for the patients. Further exploration indicates that this may be due to how HCPs conceptualise patient involvement in decision-making. The analysis found that most of the HCPs tend to equate it with patients' agreement with and/or adherence to the HCPs' recommended management.

> *Their agreement, that's what important. Rapport, of course, is also important. That's why we need to communicate with them. But, the most important thing is for us to get their agreement. If they are the one that says it is hard and what not, usually it will be less successful. But if the patients agree, as we*

managed to convince them, they usually have the desire to improve themselves. (HCP13, diabetes nurse educator, CC)

As shared by many of the other HCPs in this study, HCP13 believes that the main aim of involving the patient in decision-making is to secure their agreement with her recommendation. This understanding is much more akin to obtaining consent, which is widely used in the current Malaysian healthcare system, compared to shared decision-making (Ng et al., 2013). However, according to S. N. Whitney, McGuire, and McCullough (2003), despite sharing the similarity of respecting patient autonomy in making a decision about their treatment, shared decision-making is more preference-sensitive in comparison to informed or simple consent. Thus, due to HCPs' equating of shared decision-making with the obtaining of patient consent, HCPs' efforts, which include building a good interpersonal relationship and fostering patients' sense of comfort and trust, as asserted in the above account by HCP14, are usually geared towards ensuring that the patients agree to the recommended management (as explained in Chapter 4) as opposed to encouraging them to share their preferences, values and beliefs about the management decision under discussion.

On the other hand, shared decision-making is important when determining patients' lifestyle modification as their preferences and values are greatly related to the suitable option (S. N. Whitney et al., 2003). Compared to medication or other medical procedures, lifestyle modification mainly involves behavioural change on the part of patients, for which HCPs can only provide 'prescription' and recommendations in the form of advice. Thus, it makes sense when HCP6 mentions below that it is not something they can force and that patients need to be totally convinced in order to agree it is something they need to do in order to maintain their glycaemic level.

One more important element is cooperation. Which means the patients give their cooperation, they'll do what we ask them to do. It shouldn't be only one way. It's like we are forcing them to do, but they didn't do… As for me, I hope that patients will follow. If we ask them to check their sugar, they will do it… And then, they will control their diet, so that their sugar level will

normalise. So that the patients will not develop complication too soon. That's what we hope for. We want them to have a high quality of life. (HCP6, diabetes nurse educator, HC)

If the patients don't want to discuss with us, we have to ask ourselves as a DE (diabetes educator), maybe we're lacking, in communication, as maybe we do not really connect with them. Soft skills, how is our soft skills. If we think that we already have tried our best, but still the patient is not involved, we can't do anything, really. But, if possible, those patients should come with their relatives. We'll convince the relative and maybe the patients will hear from them. If their relatives also present, usually they will also brainwash the patients. (HCP14, medical assistant (diabetes educator), HC)

In describing the main elements of shared decision-making, HCP6 emphasises the importance of patient cooperation, which she describes as patients' compliance with the prescribed treatment. Similarly, HCP14's explanation of patient involvement in decision-making represents self-management support focused on improving the self-efficacy of patients to manage their chronic illness. As such, he describes psychological influence and support so that the patients will carry out their self-management. Ahmad and colleagues (2014) found it was common for these two approaches to be perceived as similar since both are used to promote patient-centred care; indeed, both approaches encourage individuals to be involved in managing their own illness and are commonly intertwined with patient management. Ahmad and colleagues (2014) further highlight that even though these approaches (shared decision-making, obtaining consent and support for patient self-management) are commonly intertwined and employed in conjunction with one another in an effort to operationalise patient-centred care in the practice, the way in which the approaches are understood has implications for their implementation. This is because each approach has different objectives, meaning they each require different measures.

5.3.1.2 Superiority of the recommended option

Apart from HCPs' conception of the term shared decision-making as the obtaining of consent and self-management support, the other important reason why HCPs focused more on their efforts to secure patients' agreement and compliance, in contrast to

identifying an option aligned with the preferences and values of the patients, is their belief in the superiority of their recommended option versus other options.

> *…,but the final decision, you have to allow that to be mine, because you may not want to make that decision, but you have to trust me to know that this medicine is good for you, because you didn't go to medical college. So you may never understand the concept of diabetic retinopathy, nephropathy, you can say, "yes I know it does this to my kidney" but you don't know the fine things about it…. (HCP15, FMS, CC)*

Despite realising the advantages of patient involvement in their health decisions and allowing them to be involved in the discussion, HCP15 believes that her recommended option will be more effective compared to others due to her credentials as a specialist. This is in accordance with the assertion by Bourdieu (1986), together with Fredericks and colleagues (2012), that HCPs' expertise acts as a cultural capital that contributes greatly to their higher position and discursive power over the patients in the medical and health field.

> *Based on the guidelines, Metformin is the first choice treatment for newly diagnosed patients. Other medications also have side effects. So usually, the doctor will start Metformin for new patients at the minimal dosage. If patients still can't tolerate, then only the doctors change to other medication. (HCP8, diabetes nurse educator, HC)*
>
> *I'm a disciplined person. If there is a guideline, I will follow. I will not follow if the resources are not accredited. But if it can be proven as good, scientifically, I will follow. (PT10, 35-year-old Malay man, HC)*

Besides, HCPs make recommendations based not only on their medical and health knowledge but also on guidelines employed at the national level, mainly the Malaysian CPGs, as demonstrated in the above account from HCP8. It was also mentioned in Chapter 1 that Malaysians are increasingly seeking more information and evidence as they are no longer comfortable with ambiguity (Ken & Ying, 2013). Thus, the establishment and usage of the Malaysian CPGs in making management decisions for patients is based on empirical research and the recommendations of

renowned international medical and health bodies such as the IDF, ADA, Trafford NHS Healthcare Trust and others, which are taken into account by the MEMS (2016). This approach is also aligned with the Malaysian need for rules, protocols, guidelines and schedules as a means of providing more assurance in relation to the prevention of unwanted effects (Hofstede, 1980).

However, the belief of both patients and HCPs in the superiority of HCPs' recommended option due to their technical expertise and based on the scientific guidelines may serve only to strengthen the disparity between patients and their HCPs in the hierarchical structure of healthcare (Bourdieu, 1977). This reinforces not only the paternalistic manner and content of the interactions of HCPs with their patients (as explained in Chapter 4 and the following subsection 5.3.1.3), but also the way in which patients interact with them, whether or not this is intentional (Bourdieu, 1986; Shim, 2010), as illustrated in the above account from PT10.

5.3.1.3 HCPs' paternalistic style of communicating (verbal and non-verbal)

The previous subsections of 5.3.1.1 and 5.3.1.2 described the increased possibility of HCPs' misconception of different approaches to patient-centred care and their belief in the superiority of their recommended option, thus leading to a more paternalistic style of communication among them. Chapter 4 mentioned some of the communication styles that can be considered to be aligned with paternalism, including biased information that leans towards the recommended option and HCPs' use of threatening messages. This chapter further presents and discusses the other styles found in this study that hinder patient involvement in decision-making.

> *Sometimes we have to be stern. Slow talk doesn't work. We have to "up" it a little bit. If slow talk does not work, we have to be a little bit firmer. It's always been like that. But they'll surrender. I think, they'll surrender. Because I have the facts in front of my eyes. I can't simply say it. When we're in the first appointment, they were not convinced, they don't want. Still, they win. But, one or two visits later it's like they lose and say "I will". Still, we manage to convince them... (HCP12, medical officer, CC)*

HCP12, for example, believes that HCPs must be strict in order to ensure that patients who continually refuse the option they consider to be the best are eventually convinced and agree to it.

> *Certain things, which relate to wrong decisions made by the patients, so I can't agree with them. For example, if their sugar level is high, then I will be strict to them and I would not let them make their own decision...I'll be strict in term if sugar control, I'll tell them they can't take it anymore, especially if their sugar level is consistently high, 11, 11, 11. So, if he still drinks sweet drinks, of course, it will stay high. So when they see the doctor and the sugar is high, it means the dietitian is not effective. (HCP4, dietitian, SC)*

HCP12's persistence in having her patients agree with her recommendation and using an authoritative approach to obtain their agreement is shared by many, including HCP4. Indeed, HCP4 is one of many HCPs concerned with the potentially graver consequences of patients' chosen management option over their recommended one, as it is their duty to be *"... responsible for whatever form of therapy is given to patients"* (*Code of Medical Ethics*, 2002: 8). As accountable HCPs, it is also their duty to protect their patients from any harm they foresee that the patients themselves may not yet understand. Thus, as a good advocator for their patients, these HCPs feel compelled to get their patients to agree and carry out the recommended treatment. Nonetheless, in the event that complications begin to emerge in the future, there is also the possibility of their patients and colleagues claiming they are not good at doing their job of managing their diabetes patients, as can be seen in the above account from HCP4. These findings epitomise the dilemma faced by HCPs with regard to the extent to which patients should be involved in making decisions about their diabetes management.

Furthermore, the data collected from the patients clearly illustrate the impact of HCPs' strict communication style on patients' intention, attitude and practice of becoming involved in making the decision.

> *The doctor just now seemed to be serious. So I'm scared to ask. It depends on the doctor. If the doctor seems to be friendly, I will ask. If the doctor is like just*

now, he seemed to be a little bit firmer, so I'm afraid to ask. Despite having questions, I will not ask. … When the doctor is firm with us, we will become scared and only then we realise. (PT22, 34-year-old Malay woman, HC)

The description by PT22 is comparable with the findings by Eldh, Ekman, and Ehnfors (2006), and also Frosch and colleagues (2012), which suggest that it is common for patients to feel uncomfortable in having a discussion with HCPs who portray themselves as superior and who fail to create a sense of partnership in their relationship with their patients.

Dr K is really fierce. She's not really fierce, more too strict. The other patients in my obesity group also complain if they get Dr K. But actually, there is a benefit when we meet her. Sometimes, we'll be closer to her as she's straight to the point. She said, "You have this problem. So, you have to do this, this and this. If not, this, this and this will happen". There's no hidden information. She'll tell us it all... it depends. Surrounding factors and emotional factors. We've waited for a long time to see the doctor and sometimes we can even lose our temper just by waiting. And when we meet with the doctor, he/she scolds us, which make thing even worse and we become even more sensitive. So we just ignore them. (PT12, 29-year-old Malay woman, HC)

Furthermore, the above account from PT12 contends the assertion by Laverack (2009) as to the usefulness of HCPs' domination in ensuring patients' adherence to the agreed course of management. Again, even though this patient believes that her physician uses her power for her benefit and appreciates her transparency in conveying the information, the physician's fierceness has nevertheless had a negative effect on her. This patient not only expressed her emotional distress but also admitted that she would ignore the instruction and advice given by physicians, which could be termed intentional non-adherence. Despite Laverack's (2009) claim that HCPs' dominance can be beneficial and may be considered a 'healthy' power in certain situations, the above finding indicates that it may also lead to a patient's dependence on their physician, which not only reduces that patient's cognitive ability and self-efficacy but also affects their emotional status, something which was also suggested by Seligman (1975).

They might not tell their doctors, they're afraid, they cry. If they meet with their doctors, they cry. When the doctor informs them of complications, they cry. There are some doctors who take a safe side and who don't want to talk about complications. They want to please their patients, so they just keep quiet and the patient wouldn't know. Fierceness is needed nowadays, in my opinion, because I noticed that when they come and see me, they complain that the doctor in this room was fierce, but they are the ones who comply. That's what I noticed. But we have to look at what kind of fierce, because patients like some types of fierceness, as they think that the doctor actually gives them reminders. We have to look at each doctor's approach. But, actually, it's good for the doctors to be fierce, as the patients are the ones who will control. Most of the time. (HCP4, dietitian, SC)

In contrast, for HCP4, despite her realisation of the negative effects of physicians' fierceness towards patients, she believes that the benefits of this approach outweigh any negative effects. She emphasises how a physician's fierceness will serve as an impactful reminder for patients regarding the severity of their problem and that it will encourage them to follow the recommended management. She thus perceived it to be the best option for patients. This claim was made by HCP4 based on her experience of working with cases of controlled diabetes; indeed, she had witnessed patient impacts that she believed could be attributed to physicians' fierceness.

5.3.2 Permissive HCPs

Despite the findings in Chapter 4 and previous sections of this chapter identifying paternalism as the prevailing approach in the current management of patients with diabetes in Malaysia, with shared decision-making remaining largely unfamiliar, it can also be sensed that most of the HCPs have started to embrace certain elements of shared decision-making and are permitting patients to become involved in choosing their own management since they have started to value the involvement of patients in managing their own chronic illness. The below accounts by HCP5 and HCP4 suggest some level of acceptance and adoption of shared decision-making among HCPs as they believe it may empower patients to better manage their T2DM. HCP4 has also witnessed this positive result of working together with her patients in making decisions.

Because I think it should be a two-way process, not just the doctor saying, "You have to do this or that". I think they should understand the disease and then they should be empowered, they should have the power to change the disease itself. (HCP5, medical officer, SC)

For example, if we suggest something to them, and they ask whether they can do this, this and this, we can see the compliance of the patients. Because they feel that those things are more practical to them. As compared to when we are the ones that suggest, they may feel like, I didn't do all of these things at home. So if it's like that, we can see that the patients who didn't involve, they may not turn up for their follow-up, because we can see that their sugar is not controlled or the sugar level is still high when they come for the second time. So, for those who are involved, we can see more (improvement), because we discuss with them what they can do at home. (HCP4, dietitian, SC)

5.3.2.1 HCPs' views and beliefs about their patients' characteristics

The permissive attitude and behaviour of HCPs with regard to shared decision-making is found to be influenced by their views of their patients' characteristics. Based on their judgement of patients' characteristics that they gather from the patients' records, their initial interactions with them and a brief observation of the patients' behaviour, these HCPs will usually determine the extent to which patients can be involved in making their management decision.

We will discuss about their treatment if they seem to be educated. For those educated patients, mostly we'll discuss with them. For those who are not highly educated like old ladies or old men, yet they have the initiative to improve their health, like security guard, low-income people, I will not instruct them to buy expensive things, I'll adjust it, for example, cream cracker, cheaper options. As for the milk, I don't mind whatever brand, as long as it written low-fat milk. (HCP10, dietitian, CC)

The above account by HCP10 clearly reflects how her behaviour in terms of involving her patients in discussing their dietary plans is heavily dependent on the patients' characteristics. For those whom she perceives to be highly educated, the interaction will be two-way and discussion will be more extensive, which is a good indicator that she is allowing these patients to be more involved in planning their

dietary plans. This compares to patients whom she regards as being less educated and who are older, where there is more limited opportunity for discussion. The advice on dietary plan adjustment is given based on her judgement of patients' difficulty and limitations and in the absence of a thorough discussion with them. This style was commonly detected throughout this study and may indicate the disadvantage at which less educated patients are placed and the difficulty they have in attempting to be more involved in the discussion.

> *Most of our patients, some are very good, some are, when we do get the ones that transferred in from private, I find the ones that transferred from private are more educated and those are English speaking are more educated so they have access to Google but the elderly, majority when they are don't understand and it's hard for us to discuss treatment with them. (HCP5, medical officer, SC)*

HCP5's account emphasises the regularity of HCPs' behaviour towards shared decision-making based on patients' level of education. Through her experience of dealing with different types of diabetes patients, this physician concludes that patients who come from private institutions and who are more proficient in English are better educated and are usually more active when it comes to discussing their management. She also associated these patient characteristics with the individuals having greater access to information on the Internet. Such patients usually come from more affluent communities (Thomas et al., 2011) and have better economic and cultural capital (Bourdieu, 1986; Shim, 2010). Based on her experience, these patients were also described as having a higher capacity to share the responsibility for making decisions about their diabetes compared to less privileged and older patients. Thus, she seemed to be more open to the idea of having a discussion with these types of patients. Based on an assertion by Bourdieu (1984), this is common as it is easier for the power and responsibility for making a decision to be shared among people who come from the same social class as they tend to have a similar level of knowledge and skills.

HCP10, in addition to several other HCPs in this study, also mentioned and shared the patients' socio-economic status and age. Despite attempting to ensure that the advice given suited the patients' preference, needs and values, it can nevertheless be seen from her account that advice was given as an instruction. There also appeared to be only limited involvement of elderly and/or lower-income patients, as HCP10's advice was made based on her assumption that these patients would not be able to afford or not be willing to buy certain types of food. Nonetheless, the findings of previous studies have indicated that patients with lower levels of education, the elderly and patients with more serious illnesses tend to prefer decisions to be made by HCPs, which can in turn justify their limited involvement in making the decision in this study (Auerbach, 2001; Cole, Wellard, & Mummery, 2014). Besides, the HCPs' assertion of their greater tendency to allow the involvement of patients who can converse in English and who have attained a higher level of education can also be seen in various patients' accounts, with that of PT16 below as an example.

> *They will listen because they know that we are educated. When I speak in English, they will listen. If they are not, I will be a little bit firm. I will say, "I am the patient, why you do not listen to me?" Because I'm not type of person, "Okay, never mind doctor". We need to know our condition. (PT16, 57-year-old Chinese man, CC)*

5.3.2.2 HCPs' empathy and compassionate care

Aside from HCPs allowing patients to contribute significantly based on their positive perception of patients' characteristics, it is also found that the HCPs' sense of empathy and respect for their patients further encourages them to be compassionate towards them.

Putting themselves in the patients' shoes

> *... It's quite difficult sometimes to have this shared decision in the patients' management, initially. But I suppose you cannot give up. You cannot say, "oh my God, this patient". You have to make sure that the patient likes you. First, you have to treat them nicely. I always believe that. Of course when I was younger, sometimes I was angry, sometimes I was furious, but we have to*

understand as if we ourselves are diabetes patients. It's very difficult, it's not easy. (HCP18, endocrinologist, HC)

The above account demonstrates HCP18's tenacity to involve the patient in decisions despite her understanding the challenging nature of this task. This is mainly due to her recognition of her patients' difficulties in managing their lifelong T2DM and can be seen in parallel to the definition of clinical empathy by Mercer and Reynolds (2002; p. S9) as an HCP's ability to *"... understand the patient's situation, perspective and feelings (and their attached meaning)"*. The account also demonstrates how this understanding altered the way in which she treated her patients in terms of building a good relationship with them and in facilitating shared decision-making as she became more compassionate. Compassion is one of the fundamental virtues of HCPs, along with discernment, trustworthiness, integrity and conscientiousness (Beauchamp & Childress, 2013; Papadopoulos & Ali, 2016). HCP18's sense of empathy further guided her compassionate approach to her patients as human beings and not merely as T2DM cases.

Yes, for example, if we are talking about diabetes, most people will tell the patients to eat oats. It shouldn't be like that. Not all, even if you ask me, I don't like to eat oats, but we have options…We can't just simply say, "Diabetic patients must eat brown rice". No, it will be beneficial for them if they can eat it. If not, there are other ways. Maybe they can eat a lot of vegetables, high fibre food. There are ways. We can't just simply ask each diabetic patient to eat brown rice as not everybody can afford it. Because there was a patient who said to me that she can't afford to buy brown rice as she just lost her husband. It's not a big problem, as she still can eat white rice. The food combination is more important than the type of rice. The sugar will still not reduce even if they eat good type of rice, but they take it (sugar) a lot without rice. Actually, the options are very important nowadays. It's not like, "if according to this cross book, the diabetic patients should only eat oats, or brown rice or all sort of that food". We have to look at the needs of each patient, and these days options are very important for the patients. (HCP16, dietitian, HC)

The above account by HCP16 demonstrates her efforts to plan her patients' T2DM management based on their involvement, which arose as a result of her attempting to place herself in their position. HCP16's trust and attentiveness with regard to her

patients' sharing of their daily difficulties in dealing with their diabetes shaped her understanding of the different preferences and values of different patients, including the types of food they do not like to eat, their financial problems and others, thus enabling her to consider the different aspects related to the options presented to patients. This sits in parallel to the extension of social capital by Putnam and colleagues (1994), who add trust and cooperation to the elements of this capital previously included by Bourdieu. Putnam further explains that the basis of trust and cooperation between heterogeneous groups lies in their different roles during the interaction. It is the connections between these different roles that enable them to trust and cooperate with each other. A study by Shultz, Sprague, Branen, & Lambeth (2001) also highlights the importance of patient–HCP deliberation. They identified a mismatched view between patients and HCPs relating to the barriers that influence patients' adherence to their recommended diet plan. As such, HCP16's efforts to offer as many dietary options as possible, and to provide patients with relevant information that enables them to evaluate each option fairly and make a decision accordingly, become even more valuable.

No point in forcing the patients

Apparent throughout both of the Findings chapters has been the emphasis by many HCPs that the patients cannot be forced to accept a decision that has been made paternalistically. Although it was discussed in 5.3.1.3 that this may result in HCPs taking other authoritarian measures, in other instances this belief has been shown to open their minds to the importance of taking their patients' goals, preferences and values into account when making decisions.

> *Usually I will ask them first, "Can you do this every day?" If they can't, we'll make a deal. There are a lot of options, which means we don't force our patient to do exactly what we say. They have other options. Because one, we don't want the patients to default from the treatment and second, we want them to be more comfortable, "oh, this means it is not a coercion". We give options so when they have to come here again, they will feel comfortable. We don't want them to default if we force them to do it. It will be harder. (HCP8, diabetes nurse educator, HC)*

From the above account, HCP8's permissive behaviour towards shared decision-making was due to her realisation regarding patients' role and power in managing their diabetes, as they are the ones who hold the ultimate power in deciding whether or not they wish to carry out their management at home. Whether or not this role and power is acknowledged by HCPs, she was aware of the greater potential for T2DM patients to reclaim and exercise their power through non-compliance due to the high level of their own self-management at home, which was also demonstrated in a study by Bauer and colleagues (2014). Thus, she prefers to discuss different options with her patients in respect of them performing their SMBG despite the recommendation in the CPGs for diabetes patients, especially those who receive multiple insulin injections, to carry out SMBG at least three or four times daily (MEMS, 2016). Nevertheless, the CPGs also permit, indeed recommend, an element of modification to suit each patient individually. Realising this room for modification, HCP8 tried to accommodate each patients' preference, belief and values along with the recommendation from the CPGs.

The accounts by HCP18, HCP16 and HCP8 in this subsection demonstrate how their belief in the importance of patient involvement in decision-making has led to their caring attitudes and behaviours, which are recognised in the existing research as facilitating shared decision-making (Eldh et al., 2006; Entwistle et al., 2008; Lown et al., 2009). These behaviours include a willingness to listen to and trust their patients, an effort to understand and respect their patients' concerns and needs, discussing the different options available and making decisions with their patients. Similar methods are also given as components of compassionate practice by Papadopoulos and Ali (2016), based on their review of the topic. These compassionate practices by HCPs contribute positively to shared decision-making as they make the patients feel respected and treated as human beings, which is also asserted in the following account from PT10. This patient further admits that these positive behaviours by HCPs have fostered his sense of comfort with them, thus ultimately creating a sense of partnership and good relationships between patients and their HCPs (Fraenkel & McGraw, 2007; Lown et al., 2009; Peek et al., 2010).

...I am more comfortable here, they listen more. We respect each other, we are also human. We know our history, we know what happened... (PT10, 35-year-old Malay man, HC)

5.3.2.3 HCPs' facilitative behaviours and communication style in educating patients

Some of the facilitative attitudes and behaviours towards shared decision-making adopted by the HCPs have been explained in both Chapter 4 and the previous section of this chapter. In accordance with symbolic interactionism that emphasises the contribution made by social interaction to the construction of meaning and the action of human beings, this subsection highlights further descriptions and discussion to explicate those behaviours and communication styles adopted by HCPs that are found to empower patients to be involved in the decision-making process. This is in contrast to 5.3.1.3, where the HCPs' paternalistic approach was seen to hinder the practice. Although section 5.2.1 of this chapter has already mentioned patients' contribution in terms of their life experience when dealing with their diabetes, the participants in this study emphasised the importance of them having sufficient knowledge to build a comprehensive understanding of their medical condition and to make sense of the relations between their T2DM and their concerns or any problems that they are facing.

So, what I can tell them is, "For as long as you don't understand this, we will continuously be having this issue with your sugar control". And I actually tell them because some of them, wandering already, within 2 minutes. So, they are not listening to you. They go off on a tangent, you know. So, I have to pull them back, ask them back questions like in a quiz, ask them back to see whether they are listening to me or not...So I keep telling them, "This is your disease, you should be the one talking now, not me. You should be asking me a million questions, you should be scolding me, why is my sugar like this, you cannot be just sitting and staring at me." I try to empower them to get their bodies into control. (HCP15, FMS, CC)

With this in mind, this FMS is attempting to empower patients, not only by providing them with information but also to ensure their understanding so that they can apply this to improving their health, including by playing an active role in managing their T2DM. This is aligned with the notion of health literacy as described by Rowlands, Protheroe, Price, Gann, & Rafi, (2014). They assert that health literacy is the *"... key to more effective use of resources, through increased understanding of how best to access and use health services, through confidence and skills to enable decision-making that is shared between doctors and patients, through to ensuring that patients take a full role in developing services that fit with the needs of local populations"* (Rowlands, Protheroe, Price, Gann & Rafi, 2014: p. v).

Despite the previous discussion in section 5.2 highlighting that knowledge alone is insufficient to facilitate shared decision-making, previous studies have highlighted that knowledge about health, including diabetes, is very much related to health literacy. The studies indicated that it is important for patients to have this type of knowledge in order to be able to enter into fulfilling discussions with their HCPs for the purpose of deciding their own management (Coulter & Collins, 2011; Azreena, Suriani, Juni, & Fuziah, 2016). However, the majority of diabetic patients in Malaysia have a limited level of health literacy and a low level of diabetes knowledge (Azreena et al., 2016), which was also found among the patients in this present study. Ishikawa and colleagues (2009) together with Moulton and King (2010) found this to affect their ability to participate. These researchers also made the assertion that patients with a high level of health literacy have a higher motivation to seek information from their HCPs, which encourages them to communicate more during the consultation. Thus, these studies attest to the usefulness of HCP15's efforts to educate her patients, encourage their participation in the management of their diabetes and improve their health condition.

> *Firstly, we ask. The second one, we tell them, the thing that I noticed is, when we told them, "This food contains a lot of sugar", for example, on what he usually eat, we told him, "Sir, you ate this together with hot chocolate just now, which already contained a lot of sugar". So he said, "how if I eat like*

this? Is it okay"? There are patients like that. Through questions, through what we show to them, they will discuss more and more they can remember. (HCP4, dietitian, SC)

Several empowering interactions can be found within the above account. HCP4 is not only assessing patients' current practice by asking them questions and attentively listening to them, thereby allowing her to focus on the root problem, but she is also educating and providing information based on the accurate identification of the problem, thereby tailoring the approach to each patient. These behaviours will also be beneficial in rectifying the patients' misunderstanding that led to their mismanagement as the information is given in a manner that they can relate to. On the other hand, HCP4's encouraging way of asking and responding might also be why patients are more open to interacting with her. By doing this, patients are given the opportunity to explore themselves in relation to their health condition. This positively impacts on their sense of encouragement and confidence which in turn will facilitate a continuous and self-involving relationship (Aujoulat, d'Hoore, & Deccache, 2007; Maggie, 2015). This is proven by PT11 below, who admits that she is more comfortable and can better engage with HCPs that are more skilled in communicating with her.

If the person is as friendly as me, it'll be different. There will be nothing to hide as I wrote everything… Maybe I'll be more comfortable if I meet with the same person and that person is concerned about me. Asking more questions and all. (PT11, 36-year-old, Malay woman, HC)

The HCPs' acts of enquiring about her condition and responding positively to her concerns have encouraged PT11 to be more active in discussing her diabetes, especially if she meets with the same HCPs. Similar to the HCPs that were included in the previous subsection of 5.3.2.2, the HCP accounts in this subsection identify the essence of good communication skills among HCPs, which can be described as approachable and compassionate (Papadopoulos & Ali, 2016).

This account from PT11 also illuminates the importance of HCPs' communication style when interacting with Malaysian patients, which is aligned with another study

that was carried out in China (Ting, Yong, Yin, & Mi, 2016). As mentioned in Chapter 1, Malaysia, as an Asian country, has a high-context culture in which implicit communication is more valued than direct communication (Hall, 2000). Thus, besides the verbal information that HCPs try to convey during their encounters with patients, most patients also evaluate their HCPs' non-verbal styles (including their tone of voice, body language, eye contact and facial expressions) in determining their level of approachability and tolerance, which was described as friendliness by PT11. This will further influence patients' level of involvement in the discussion about their diabetes condition.

> *Some people google nowadays, and everything is there, so some people do come out with their own, "Can I take this? Can I do this? Can I do this?" We have to listen too, we cannot be authoritative and say, "you this, this and this". No. It has to be two-way, but again, coming back to resources. So, there are not many options at this place. At this level, at my level. So, we have to use the resources which are available. Unless they are willing to buy those drugs outside like other good ones, they're welcome to. There are one or two who are willing to buy. So, we just, we do welcome them. Most of the patients cannot. So, they go with what is available here. (HCP12, medical officer, CC)*

HCP12, realising the importance of shared decision-making despite the limited options available at public facilities, stated that her patients were given the opportunity to enquire about options that they perceived would suit them better and to seek these away from the facility, if, after having discussed the matter, they chose to pursue them. However, relatively few patients were able to seek their preferred options outside the facility due to the increased cost involved. In spite of this, HCP12 tried to ensure patients were given a sense of being heard and tried to address their concerns accordingly. This may not only increase their feeling of comfort as previously mentioned in 5.3.2.2 but also may improve their sense of empowerment to express their opinion and be involved in a discussion about their diabetes management (E.S. Rogers et al., 1997; European Commission, 2012).

> *Usually I will ask, when I can see that the sugar is out of control and I have to troubleshoot, I have to ask, I have to find out why, is it because of the*

> *injection technique or so on and so forth. So, some of them, actually not many people told me that the needles are expensive. They don't come out with that. Maybe 1 or 2. But, a lot of people when I asked to do the SMBG, the strips, that's the one that they said are expensive. But not needles, even when I asked why they used too long, they said "Oh, I didn't know about it"…Some will open up when we ask them why this is happening, then they will open up. They will be like sobbing here. I find that if you are softer with them then they will open up they will tell you why. (HCP5, medical officer, SC)*

Furthermore, by means of a thorough assessment, HCP5 is able to detect her patients' non-compliance, which provides her with the opportunity to properly address their main problem. By asking her patients questions and taking into account their experience in managing their T2DM, this HCP has the opportunity to investigate the non-medical reason behind her patients' uncontrolled glycaemic levels. Besides, HCP5's account also indicates that some HCPs realise that a friendlier approach will facilitate their patients' willingness to share their problem, as previously asserted by PT11 in this subsection.

> *That is quite common, the ones who didn't ask much, we'll push them slowly. Ask, what, why they don't want to comply with medication. Actually for those who are less educated, it's not that they don't want to ask, sometimes they're shy, as they don't know what to ask. So, from there we'll tell them. (HCP14, medical assistant (diabetes educator), HC)*

A handful of the HCPs in this study encourage patients to ask them questions in an effort to make the patients feel comfortable with them, which then encourages further discussion. This is comparable with findings by Abdulhadi, Al Shafaee, Freudenthal, Östenson, and Wahlström (2007) highlighting the difficulty experienced by patients in communicating with their HCPs as they are not encouraged to ask questions, thus resulting in an HCP-centred encounter.

5.4 Physicians versus non-physicians

Most of the HCPs also valued patients' sharing of information as it made their encounters easier. Throughout both of the Findings chapters, it was described how patients' involvement in decisions is affected by the different responses or treatment offered to them by their HCPs. The findings also indicate that there were noteworthy differences in terms of patients' engagement with their physician compared to their non-physician HCPs.

> *The doctor's explanation just now was not as detailed as this diabetic nurse. With the diagram, it became very clear to me how to take it*
>
> *No, and I also didn't ask him. I only said to him, "sometimes I forgot, doctor". That's why I asked the diabetic nurse. I felt more comfortable with them, because the way they interact is different. The doctor was way too serious. Actually, I would talk to him if only his face was more relaxed. If he was friendlier, maybe I would not be too afraid to ask. (PT22, 34-year-old Malay woman, HC)*

> *Patients are more open here compared to when they meet with physicians, specialists. Sometimes, I don't know who the management is over there, but here we try to be their family member. We'll try to be close to them. There are ways in which patients will be more open to telling their main problems. So, actually, the patients will tell us A-Z when they come here, as compared to the medical clinic. (HCP14, medical assistant (diabetes educator), HC)*

The account from PT22 illustrates that some patients are more comfortable with non-physicians than they are with their physicians. As indicated by PT22, patients react to the way they are treated by different HCPs. This might suggest that some patients are more comfortable sharing their problems with their non-physician HCPs as these individuals tend to be more welcoming and have better communication skills. This was also supported by HCP14, who verbalised his willingness to spend extra time connecting with and building a better rapport with his patients.

> *DRC is okay. There are some doctors who look friendly, I will ask them more. But if I get the serious one or doctors who seem to want to hurry, I will not ask much. (PT11, 36-year-old Malay woman, HC)*

There were also a few cases in which patients perceived that their physician would not be able to attend to their concerns due to them not deeming them to be important and the fact that they had other patients to see, thus creating another barrier to patients verbalising their concerns to their physician. Instead, patients with access to other HCPs, PT11 for example, preferred to share their concerns or doubts with these HCPs.

> *If that happens, we'll consult with the doctor. Sometimes, some patients have side effects from Metformin, so we'll consult with the doctors so that they can prescribe them another type of Metformin. (HCP6, diabetes nurse educator, HC)*

HCP6's account corresponds to one of the attributes listed by Bu and Jezewski (2007) which emphasises that as advocates acting on behalf of their patients, HCPs, particularly nurses, play an important role in maintaining their patients' rights and values, especially when the patients themselves are unwilling to do so. In these cases, non-physician HCPs, including nurses, appear to play the role of patient advocates, providing further support to patients so that their verbal complaints can be better managed, as reflected in the following account. However, as previously mentioned, not all patients have access to HCPs other than their physicians, especially patients in primary health clinics whose interactions with pharmacists, dietitians or even nurses tend to be brief, one-off or based on a referral from physicians.

> *I don't know about other people. I see that there are some doctors that we can discuss, there are some who don't even want to talk. (PT24, 44-year-old, Malay woman, HC)*

Nonetheless, similar to the accounts by other patients in this section, PT24 also highlights that patients' lack of engagement during their encounters with physicians is not merely because of the physicians' higher status but is also due to their personal non-facilitative treatment of the patients.

5.4.1 Section summary

This section further presents the understanding, beliefs, values and characteristics of the HCPs that are found to shape the different practices of involving the patient in making the decision. These include their conceptualisation of shared decision-making and the higher value placed on their own expertise and recommendations compared to those of the patients, which substantially hindered the practice. On the other hand, those HCPs who facilitate patient involvement usually have a stronger belief in the benefit of their patients' involvement and that the patients have what it takes to be involved, in addition to their empathy in understanding the patients' difficulty in managing their T2DM as a lifelong illness.

5.5 Chapter summary

Through the adoption of Bourdieu's work in exploring the elements related to the practice and understanding of patient involvement in decision-making, this chapter relates the practice to the patients' and HCPs' character or habitus and capitals that have been structured by their past experience, motivation, thought process and embodiment of social expectation. Following the exploration, the views, values and beliefs that are commonly shaped by their habitus and capitals are found to further influence their practice of patient involvement in decision-making.

One of the factors found to be most apparent in terms of influencing the practice of patient involvement in the decision is the value placed by the participants on both their own and their counterpart's expertise. Generally, the technical knowledge of HCPs is found to be valued more highly than patients' experiential knowledge, thereby hindering patients from becoming involved in their decisions. This is also aligned with the lack of recognition of patients' experiential knowledge as their cultural capital in comparison to HCPs' technical knowledge, which is accumulated through the formal education system (Bourdieu, 1986; Shim, 2010). As such, the perception arises that the recommendation given by HCPs is always the best and that

patients should agree to it. This chapter also further highlights how the HCPs described shared decision-making similarly as obtaining a patient's consent for their recommendation and support for self-management. In turn, the HCPs' effort is often geared towards the securing of their patients' agreement and adherence.

For the patients, it has been demonstrated that their sense of self-empowerment drives their proactive behaviour in ensuring that their concerns, preferences and values are taken into account in the decisions. However, it also appeared that some of the patients struggled in their effort to do so due to being faced with authoritative HCPs. Besides, patients' involvement is also heavily dependent on the degree of importance they perceive regarding the involvement and/or the decision. The patients were found to be more active if they perceived that their concern or problem posed a risk to their overall well-being or if they required an intervention from their HCPs. In contrast, they tended to be more passive if they believed they had no right to choose based on the nominal amount they paid for the service they received from public facilities. In addition, patient involvement in decision-making was found to be limited if the patients wanted to be perceived as good, particularly by their HCPs, in order to preserve their relationship. The following Discussion chapter further synthesises the findings of the current study by placing it within the existing body of literature and theoretical framework.

CHAPTER 6: DISCUSSION

6.1 Introduction

This study has aimed to address the lack of research on patient involvement in T2DM decision-making in the Malaysian context by understanding patients' and HCPs' experiences and perspectives on the matter. Patient involvement in decision-making is considered to be one of the main components of patient-centred care as the ubiquitous approach promoted by the WHO in its effort to improve the quality of care and appropriate use of services (WHO, 2007; Stacey et al., 2014; McCormack & McCance, 2017). Based on the data presented in Chapters 4 and 5, awareness of and support for the involvement of patients in their own T2DM management has generally been demonstrated by both the patients and different groups of HCPs. However, further descriptions of their understanding and experience of it indicate that the matter is being viewed and practised differently, with biomedical care and paternalism being the main approaches. In Chapter 5 the factors that influenced the views and practice were further explored and explained.

This chapter further elaborates the key points from both of the Findings chapters by linking them back to the existing literature, related models and theories, together with the Malaysian social and cultural background. The discussion in 6.2 and 6.3 relates to the findings from Chapter 4 and highlights the issues considered to be important regarding the current practice of patient involvement in decision-making at the study sites. Section 6.2 contains further discussion of the key elements that further reflect the lack of patient involvement in decision-making, notably the patients having only limited involvement at the beginning, when the agenda of the consultation is set; the lack of information exchange by both sides; and the emphasis on the HCPs' recommendation and patients' agreement with that recommendation. In discussing these key findings the existing shared decision-making models are extensively referred to as ideal models for patient involvement in decision-making. Section 6.3 further discusses the most alarming consequence of the current lack of

patient involvement in decision-making as identified from both of the Findings chapters, namely the disassociation between patients' agreement and their adherence.

This is followed by sections 6.4, 6.5 and 6.6. Based on symbolic interactionism as the theoretical underpinning of the study, together with Bourdieu's social theory and work on power, these sections discuss three key factors that were found to influence the practice: (1) the patient–HCP interpersonal relationship and communication; (2) the perceived roles of HCPs and patients; and (3) patient–HCP power relations in decision-making. The discussion in 6.6 draws on the work of Bourdieu on power relations and the power dynamic between the patient and HCP in making the decision. Finally, based on the discussion of the key findings of the study, this chapter brings forward the contribution of this study to the existing shared decision-making concept in terms of facilitating its effective implementation in the study context.

6.2 Patient involvement in decision-making

To reiterate, the findings of this study suggest that patient involvement in decision-making in this study context ranges from HCPs' paternalistic decision-making, shared decision-making, through to patients' informed decision-making. Nevertheless, further comparison of the participants' descriptions of their decision-making experience with the existing decision-making models, which were previously presented in Chapter 2, indicate that HCPs' paternalistic decision-making appears to dominate the way in which decisions are made, with only limited active involvement and contribution from the patients themselves.

6.2.1 Patient involvement in agenda setting

Significant mention was made during the interviews of patients' involvement in identifying the problems. Comparable to the assertion by Entwistle and Watt (2006), it was apparent in the patients' descriptions of their experience relating to this activity that their involvement is greatly valued by both themselves and the HCPs, as

shown by the fact that the patients were actively involved in responding to their HCPs' enquiries about their concerns and identified problems. This was done with the main aim of assessing signs and symptoms and/or complications related to their T2DM, along with any T2DM-related problems they encountered between their follow-up visits. However, the patients' accounts illustrate a perception that the concerns they shared, relating mainly to side effects, pain, stress and sexual dysfunction, in addition to their needs and preferences, were often not properly addressed or given sufficient attention by their HCPs. Similarly, a superficial exploration of patients' concerns, problems and needs, together with a lack of consideration of the above-mentioned verbalised psychosocial concerns from patients, is also apparent in the HCPs' accounts.

The extra attention paid by HCPs to their patients' biomedical status and the lack of consideration of their psychosocial problems when setting the agenda for consultation can be linked to both the traditional biomedical model and modern evidence-based medicine. Here, the main aim is to treat the disease by restoring patients' physical function, which appears in their biomedical results or during a physical assessment (Szasz & Hollender, 1956; Bensing, 2000). Since the HCPs' encounters with the patients in this study context were usually brief and there was only a slim chance of them meeting the patients again at their next follow-up, some of the HCPs (e.g. HCP12, subsection 4.2.2; HCP19 in 4.2.4) felt the need to offer a quick fix capable of producing an improvement in their patients' biomedical status. As previously discussed in section 4.2, this was more apparent among the medical officers who work on a rotation basis and who typically have only around five to ten minutes to spend with each patient. However, further exploration revealed patient involvement in identifying the problems and greater consideration of patients' non-biomedical problems to be crucial since the majority of them attended clinics for follow-up appointments. As such, most of the patients did not have any major health problems but they did have a range of concerns that did not appear in their test results and/or were not physically visible and thus could not be considered as requiring immediate intervention. Besides, their main concerns related to T2DM may

vary and may not be as apparent as for patients with an acute condition since each individual faces different challenges in their day-to-day T2DM management.

Similarly, the existing shared decision-making model lacks any description of patient involvement in determining their problems. This may be due to an existing understanding that shared decision-making between patients and their HCPs begins after the agenda for the consultation has successfully been determined (Charles et al., 1997; Elwyn et al., 1999). Nonetheless, the findings of this study suggest that a lack of exploration and consideration of patients' concerns and needs at this stage tends to adversely affect the overall process of decision-making and patients' adherence to any decisions that are made within this encounter. This is because, similar to the findings by R. O'Brien, Wyke, Guthrie, Watt and Mercern (2011), there is a disparity in the nature of patients' and HCPs' concerns and their agenda for the encounter. Besides, the findings of this study also support the assertion by Bugge and colleagues (2006) that the lack of an information exchange on patients' problems may lead to patients worrying unnecessarily that the severity of their problem is not being adequately explored. There is also the possibility that inadequate patient involvement at this initial stage may complicate the effort to develop a comprehensive shared understanding and good patient–HCP relationship. Consequently, many of the patients in this study reported a diminished intention to discuss their problems and concerns not only in that specific encounter with their HCPs but also in their subsequent clinical encounters, despite them continuing to be very concerned about the problems.

These findings accentuate the need for the shared decision-making model to also focus on involving patients in the identification of problems and concerns that may give rise to the need to make new decisions, as suggested by Murray and colleagues (2006). By examining the original work of Charles and colleagues' (1997) shared decision-making model in general practice, Murray and colleagues (2006) noted that the 'additional task of deciding an agenda for a consultation' should be included as one of the elements of shared decision-making. This is also extended to activity in

defining or explaining the problem, as listed by Makoul and Clayman (2006) as one of the essential elements in their integrative model of shared decision-making in medical encounters.

6.2.2 Information exchange

Another critical element of the involvement of the patients in this study in their decisions involves the exchange of information between the patients and HCPs, where there appeared to be a lack of information sharing by both sides. This serves as another indication that shared decision-making is not fully practised in the current management of T2DM at the study sites, despite it being highlighted as one of the important components within many of the shared decision-making models (Charles et al., 1997; Makoul & Clayman, 2006; Elwyn et al., 2012).

6.2.2.1 Information from HCPs

The findings of this study indicate that on most occasions, the patients were neither presented with other options nor were they given sufficient information. As such, it is debatable as to whether any decision made on the basis of such a lack of information from the HCPs can be considered as a shared decision; indeed, Zanini and Rubinelli (2012) asserted that for patients to be truly involved in and to benefit from discussion about the different options available for their individual condition, the information provided should be sufficient and unbiased. This is crucial in allowing patients to have the correct understanding of all of the available options and for them to construct their own point of view, thereby enabling them to effectively choose their preferred option and to then discuss this further with the HCPs. Thus, in the absence of sufficient unbiased information being provided by HCPs, patients, including a large proportion of the patients in this study, are unable to discuss the decision, vocalise their doubts, arrive at their own preferred option or reach any justification for it. As a result, a common situation is for discussions relating to decisions to be based on HCPs expressing their point of view, with patients not being able to raise any doubts in relation to this viewpoint. This was demonstrated in the previous subsection of 4.3.4, where some of the patients often felt they had no choice other

than to take the recommended option, despite having sensed an element of disconnect between the recommended treatment and their everyday life. Similar to the outcome of patients' lack of involvement, this can lead to a greater potential for patients' non-adherence, whether or not they had willingly decided to agree in the first place. These accounts can therefore serve as the basis for stating that the information is provided mainly to inform the patients about the treatment option/s and not really to enable them to participate in making a decision. Slovic (1995) suggests that to facilitate patient involvement in decision-making, the information provided to patients should enable them to construct their own view and preference based on their values and beliefs and should not merely guide their expectations with regard to their illness and its treatment.

On the other hand, the findings in sections 4.3, 4.5 and 5.2 revealed the likelihood of patients experiencing frustration as they were not able to pick their preferred option out of a variety of options that either were or were not presented by their HCPs for a variety of reasons, despite their acceptance of the condition. This corresponds to the assertion by Peters, Dixon, and Hibbard (2007) that too much information may lead to worse decisions being made due to patients' cognitive and emotional overload. They may feel overwhelmed and anxious by the sheer amount of information received from the HCPs. Nonetheless, Rosenbaum (2015) argues that this should not be a reason for patients to be uninformed. Instead, she suggests that HCPs should seek to manage their patients' cognitive and emotional struggle in addition to providing sufficiently transparent information. In doing so, it is important for HCPs to take into account the patients' concerns and needs, level of health literacy and ability to comprehend and apply the information to their own clinical issues (Epstein, Fiscella, Lesser, & Stange, 2010).

The importance of information provision by HCPs can be identified in this study. The patients appeared to have access to other options and information about their T2DM management from resources other than the HCPs, including from family and friends, the media and the Internet, in addition to from their surroundings, and these

may or may not be shared with their HCPs for further deliberation. In this study context, besides other conventional treatment options, the patients appeared to also consider traditional medicine as a viable option for managing their T2DM. In comparison to the West, traditional medicine is both widely used and easily accessible in Malaysia, regardless of whether or not it is combined with the patients' conventional medicine (Othman & Farooqui, 2015). The use of this type of medicine by T2DM patients in Malaysia is widely known and has been addressed in the recent CPGs by MOH Malaysia. However, due to a lack of solid evidence as to its effects, the CPGs do not recommend traditional medicine as an option for managing patients. Nonetheless, the guidelines do recommend that HCPs assess their patients' usage of traditional medicine. The excerpt from PT15 in subsection 4.3.1 is one example of where the patient found out about traditional medicine from his workplace. For this patient, it seemed that the combination of the lack of information from the HCPs and the information about traditional medicine that he had gathered on his own initiative from outside the healthcare system had increased his potential for non-adherence. It had also led to him developing an undesirable impression of his HCPs as he raised the question during the interview of how the decision had been arrived at to increase his insulin dosage. Subsection 6.3.1 contains further discussion on the impact of this lack of information sharing on the patients' views of their HCPs.

Furthermore, on the rare occasions when options other than the HCPs' recommendation were presented, they were generally introduced after the recommended option. In many cases, other options were considered only after the patients had been deemed unable to perform or accomplish the first option, or when further assessment or evaluation revealed that the option recommended initially was not suitable for the patient. Overall, it was also detected that other options were not routinely presented, especially when it came to the intensification of pharmacological modalities, including the increased dosage of medications and the addition of oral medication. The other most common areas in which inadequate provision and discussion of information by the HCPs were found centred on the unwanted risks or side effects of their recommended option, as presented in section 4.3. In some of these cases, the HCPs' lack of sharing and discussion of this information, thereby

favouring their recommended option, might relate to their effort to obtain patients' agreement and adherence to the recommended option.

Nonetheless, obtaining the agreement of patients might not have been the only reason that the HCPs in this study did not share and discuss the options and related information with their patients. It may also have been due to the HCPs considering the information to be unimportant or inappropriate, their belief that the information they provide to patients should be based on their own professional expertise and responsibilities, or otherwise due to time constraints. These potential reasons are in line with those found in a study by Bugge and colleagues (2006). Claramita and colleagues (2013) also suggested that a lack of information and options being presented by HCPs is associated with their lack of awareness of unusual conditions or problems. However, this study further found that some of the HCPs refrained from disclosing information that they did not consider the patient would understand. Aside from the potential impact on the patients' experience of healthcare and their perceptions of their treatment decisions, Entwistle and Watt (2006) and Frandsen and Kristensen (2002), along with Claramita and colleagues (2013), suggested that a lack of or ambiguous information may frustrate patients' efforts to carry out their management. This in turn can result in a lack of adherence among patients, which has also been demonstrated in this study. All of the above discussion in this subsection is aligned with the description of the paternalistic approach by Emanuel and Emanuel (1992), whereby HCPs share the information that they select in such a way that reassures the patient and leads to them agreeing with the treatment that they consider to be the best. Hence, it can be concluded that the HCPs hold the power to control the provision of medical information and the discussion that ensues with their patients.

Besides, it was found that the patients in this study wanted more information about options and their management. Comparable with the findings of the existing research presented in subsection 2.3.3.2, it was common for the patients in this study to ask their HCPs for the information they desired, but it was also common for the HCPs to

not fully answer their patients' questions (Peek et al., 2008; Corser et al., 2010; Hajos et al., 2011). Besides the aforementioned problems that arise as a result of HCPs' non-disclosure of information, similar to the findings by Bugge and colleagues (2006), some patients did not appear to mind that they had not received all of the related information so long as they were taken care of by their HCPs. Varul (2010) suggested that this might be due to the lack of any incentive for normalisation among patients with a chronic illness, which may then be followed by a feeling that the way in which the decision is made is insignificant. However, due to the severity of the potential ramifications of a lack of information sharing, it is suggested that HCPs ask their patients if there is anything else they may wish to know or discuss (Bugge et al., 2006), which was actually seen to be practised already by some of the HCPs in this study.

Thus, tailored decisional aids are found to be widely developed and used in the making of decisions for T2DM patients, especially in Western literature, thereby facilitating the HCPs to provide sufficient and transparent information while restricting their own domination and enabling them to elicit questions from patients on the information they want from the HCPs (Weymiller et al., 2007; Mullan et al., 2009; Drewelow et al., 2012; Branda et al., 2013; McBride et al., 2016). In Malaysia, as presented in Chapter 2, a decision aid focused on insulin initiation was developed and tested by P. Y. Lee and colleagues (2015). In this study context, no specific decision aids were used and on the occasions that a tool was used to help explain the options, the HCPs used tools that had been developed mainly for the purposes of patient education and self-management support.

6.2.2.2 Information from patients

In the shared decision-making approach, the emphasis is on information being exchanged in a two-way direction, as the information shared by the patients is considered to be equally as valuable as that provided by the HCPs (Charles et al., 1997). The information considered vital to be shared by the patients includes their concerns, needs, preferences, beliefs and values. However, in this study, the sharing

of this information was clearly lacking throughout the decision-making process, with the interaction remaining one-sided when information from the patients was shared less than that from the HCPs. Aligned with the recommendations in the existing shared decision-making models (Elwyn et al., 2000; Elwyn et al., 2012), most of the sharing by the patients in this study was heavily dependent on the HCPs' attempts to elicit the requisite information from them. Besides, it was common for the patients to refain from relaying the information to the HCPs unless they were asked to do so. As a result, the only information asked of the patients and subsequently discussed was that considered by the HCPs to be important. This may indicate the existence of power asymmetries in the exchange of information between patients and HCPs. This is where the use of a decision aid, which was previously explained in Chapter 2, is extended to help HCPs ensure that patients' views are elicited and considered when making the decision (Weymiller et al., 2007; Mullan et al., 2009; Drewelow et al., 2012; Branda et al., 2013; P. Y. Lee et al., 2015; McBride et al., 2016).

In some other cases, the patients did not share any information regardless of whether or not their HCPs asked them to do so. The following factors are some of those found to be associated with the lack of information sharing by the patients in this study: (1) patients' perception that the information is not important or does not need to be shared with their HCPs, in addition to being asked superficial questions such as 'do you have any problem?'; (2) a lack of value being accorded to their information (further discussed in 6.2.2.2); (3) their HCPs' negative responses from their previous sharing or not feeling comfortable to share with certain HCPs; (4) time constraints; (5) their forgetfulness, as they had faced the problem long before their follow-up appointment; and (6) intentional non-disclosure of information with their HCPs to serve a certain purpose (further discussed in 6.3.3). These factors indicate that sharing by patients is not determined solely by direct elicitation by HCPs but is also influenced by the implicit effort of some patients to shape the decision to suit their preferences and needs. This covert effort by patients is considered by Gaventa (1980) as their way of reclaiming power. This is further discussed in the following sections 6.3 and 6.6.

This discussion on the other factors linked to patients' lack of information sharing can form the basis of an argument that it is not only HCPs that have a responsibility to elicit information from the patients; rather, the findings of this study highlight that the competency and responsibility of both patients and HCPs are equally important so that information from the patients can be adequately shared, discussed and integrated into the decisions that are made. This is in accordance with another shared decision-making model suggested by Towle and Godolphin (1999). They also emphasised that although the patient can be taught and trained to become actively involved in the information exchange and decision-making, it is a significant challenge to refine the implementation as there is a lack of good literature on it. This is because, as presented in 2.3.3.2, the majority of the existing literature on patient involvement in decision-making discusses the information that is shared by HCPs. This is parallel to the previously developed shared decision-making interventions that mainly involved HCPs, with patients having limited to no involvement (Coulter et al., 2015). However, one intervention developed by Corser and colleagues (2007) was found to include a patient education session, which was found to facilitate patient involvement in their decisions, while the intervention itself was generally well accepted by both patients and HCPs.

6.2.3 HCPs' recommendation and patients' agreement

Many of the HCPs in this study believed that the decisions they made were shared with their patients by virtue of the fact that they had informed the patients and obtained their agreement with their recommended option, with the decisions being made based on a prior information exchange between them. Although this belief sits in contrast to the paternalism outlined by Dworkin (1972), who asserts that it occurs whenever a decision is made or a treatment is carried out without the consent of the individual, the descriptions in Chapter 4 as to how the agreement was obtained better accords with Emanuel and Emanuel's (1992) elucidation of paternalism. These descriptions include how the options and information were either presented or not presented by the HCPs, the limited elicitation of patients' concerns, needs, preferences and values, resulting in a lack of deliberation on the options, and patients

being persuaded or threatened to agree with the HCPs' recommended option. Similar to the intention displayed among the HCPs in this study, the approach that they use to obtain their patients' agreement or consent is termed 'soft paternalism' (Nys, 2008). Dworkin (1972) and Cohen (2013) further argue that some form of paternalism is needed, as sometimes individuals need to be nudged to act in a certain way in order for their condition to improve, notwithstanding that it may involve them doing something they do not wish to do. The above argument is also frequently used to justify paternalism or the effort expended by the HCPs in this study to secure the patients' agreement as it is being done for the patients' sake.

However, paternalism is often rejected due to its negative connotation, with it often being linked to the dominance of HCPs over their patients and a failure to respect patients' autonomy (J. J. Chin, 2002; Entwistle, Carter, Cribb, & McCaffery, 2010). In this context, it is linked to patients' freedom to make a decision about their T2DM management. However, Nys (2008: p. 67) states that autonomy is a very broad area, referring to respecting autonomy as *"... that one is allowed to make important life choices..."*. Yet, patients' autonomy with regard to a decision to commence insulin or a decision regarding the frequency of their SMBG differs greatly from a decision to increase a patient's dosage of oral medications, or a decision on the topic or agenda of health education during the clinical encounter. On the one hand, it is crucial for there to be a sharing of decisional authority; on the other hand, however, shared decision-making is considered to not make sense in certain situations (S. N. Whitney et al., 2003). Nys (2008) also argues that paternalism does not damage the value of autonomy; rather, paternalism safeguards patients' ability to use their autonomy at a later stage, when it may be needed for a bigger or more life-changing decision.

Besides, the effort of HCPs to attain patients' agreement with their recommendation, as opposed to deliberating with a patient to decide upon the most suitable option, may relate back to the way they conceptualise patient involvement in decision-making as presented in 5.3.1.1. This conceptualisation of involving the patient in

decision-making, which was shared by many of the HCPs in this study, leans more towards the practice of obtaining informed consent than it does towards shared decision-making, despite the patients' belief that their recommended treatment is the best compared to other suitable options, as presented in 5.3.1.2. It appeared in 4.3 that this is more common when it comes to insulin initiation, where the patients' agreement is considered to be essential as it requires their full commitment.

However, Ahmad and colleagues (2014: p. 13) emphasise that shared decision-making is dissimilar to informed consent in the way that the former refers to the *"... process by which a decision is reached"*, whereas informed consent refers to the decision itself as a legal construct where patient involvement is limited to whether or not they agree with the HCPs' recommendation (Kunneman & Montori, 2016). Similarly, Rosenbaum (2015) emphasises that agreement by T2DM patients is not only about their consent or permission; it also relates to the decision to choose different options for different conditions. Besides, in this study context, where the focus is on chronic illness, the effect of the paternalistic approaches taken by HCPs to obtaining patient agreement with the recommended option moves beyond respecting the autonomy of patients to choose, with its ramifications actually extending to when a patient is outside of the clinical encounter. The sharing of information between both sides is crucial in helping the patient to decide upon and then perform their self-management when their HCPs are not present. On the other hand, the coercive and persuasive methods used by many of the HCPs also conflicted with the shared decision-making model, which emphasises the obtaining of agreement through unbiased deliberation between patients and HCPs (Charles et al., 1997; Towle & Godolphin, 1999; Elwyn et al., 2012).

Furthermore, as discussed earlier throughout Chapter 4 and subsection 6.2.2.1, the recommended option was often presented in such a way that the patients would favour it compared to the other suitable options. This practice is contrary to the strategy proposed by most shared decision-making models that each option should be discussed in balance by informing the patients that there is no best option and that

doing nothing or not deciding anything are also viable options (Elwyn et al., 2000; Makoul & Clayman, 2006; Towle et al., 2006; Elwyn et al., 2012). Furthermore, Mendel and colleagues (2012) emphasised that not only could the HCPs' recommendations lead the patients in their study away from their preferred option, but also that these patients were less satisfied with the decision compared to those who had not been diverted from their preferred option, primarily when the recommended option was not the one they had initially preferred. Similarly, one of the most recent shared decision-making models, by Elwyn and colleagues (2012), no longer includes HCPs' recommendation as one of its elements.

In Chapter 4, it was also presented that limited assessment, elicitation of patients' concerns, preferences and values, and deliberation with patients led to the identification of a recommended option and prescription by the HCPs that may not ultimately have been the optimal one for the patients' need and condition. This may contribute to a perceived disconnect between the prescribed or recommended treatment and management and patients' everyday life, thus resulting in intentional or unintentional non-adherence, as reported in previous studies (Vinter-Repalust, Petricek, & Katić, 2004; Nair et al., 2007). However, as described in the previous Findings chapters and the previous sections in this chapter, it is seldom the case that patients share these perceived disconnects and non-adherence with their HCPs. The reasons for this lack of sharing by patients, including any perceived disconnect, have been discussed previously in 6.2.2.2. They include patients' effort to maintain a good relationship with their HCPs, previous bad experiences of sharing, patients' lack of cognitive understanding regarding what to share and what not to share, and patients' embarrassment at not being able to understand or afford the suggested treatment.

Stevenson (2003) also raises the issue of making incorrect assumptions with regard to patients' agreement, which was also identified in 5.2.4. This resonates with the argument by Charles and colleagues (2006) on the importance of cultural influences in the clinical encounter, whereby agreement is commonly given by the patients in the study solely with the intention of pleasing their HCPs in order to maintain a good

relationship with them, especially if the recommended option is forced on them or they are subjected to persuasion. Additionally, the fact that Malaysia has a high-context culture increases the potential for patients' non-disclosure of their disagreement with their HCPs' recommended option. This is because, as mentioned previously in Chapter 1, a 'yes' given by patients' may not be a true 'yes' or a reliable indication of their agreement as it may serve only to signal their understanding of the suggestion (Raelin, 2000; Hooker, 2012). Raelin (2000), together with Say, Murtagh, and Thomson (2006), further emphasise that HCPs need to use their discretion as it is common in this culture for patients to agree as an automatic response that is considered to be socially correct, polite and respectful to those who are deemed to be superior, given with the intention of saving face for both sides. Disagreement or dissatisfaction is more likely to be communicated indirectly and non-verbally and through a failure to pursue the matter (Hooker, 2012), as demonstrated in 5.2.4.

6.3 Disassociation between agreement and adherence among patients

Adherence has been defined as *"... the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle change, corresponds with agreed recommendations from a health care provider"* (Sabate, 2003: p. 3). This accords with the emphasis given earlier in Chapter 5, whereby adherence differs from compliance in the sense that the former relates to a patient's decision to agree with the option that has been chosen and recommended by the HCPs. Adherence is one of the topics that is widely discussed in the medical and health field in general and also in medical and health decision-making practice specifically, not only as a measure of the outcomes but also due to the potential burden it can exert on patients and the healthcare system as it relates to morbidity and mortality, quality of life and healthcare costs (Sabate, 2003; Joosten et al., 2008).

Similarly, in this study, adherence was a topic that was frequently mentioned by both the patients and HCPs. As explained in Chapter 4 and subsection 5.3.1, due to the continued dominance of the paternalistic approach in the way in which decisions

were made in the study context, decisions were made mainly by the HCPs, with limited deliberation with the patients. Nonetheless, the findings of this study have also demonstrated that some decisions were made with agreement from the patients. Yet this agreement was often found to be insufficient to ensure the patients' adherence, despite previous studies indicating that patients' agreement with a decision might improve their adherence (Schoenthaler et al., 2012; Stacey et al., 2014). It was pointed out in 6.2.2.2 that patients' non-adherence and their non-disclosure of this is their way of claiming ownership and control over their care. However, other factors were also found to contribute to this non-adherence and non-disclosure. This section contains greater discussion aimed at further exploring this matter in the study context.

6.3.1 Patients' non-adherence to the recommended option

As discussed earlier in 0 of this chapter, it was often the case that the HCPs used a paternalistic approach as a way of securing patients' agreement, including by providing insufficient and/or biased (i.e. manipulated or misleading) information to the patients, and by using threatening messages, coercion and/or persuasion to encourage their patients to accept their recommendation. These paternalistic methods of delivering information often led to patients agreeing to the recommended option without them having the sufficient understanding, knowledge and skill to consistently carry out their management. Additionally, since many of the patients in this study have a low educational background, they may not have been able to understand the non-individualised information with which they were being presented and to then apply this as knowledge and skills in facilitating them to carry out their management. This is one of the main reasons for the poor adherence among patients in this current study and aligns with the findings of previous studies (Jeavons, Hungin, & Cornford, 2006; Williams et al., 2008). However, it was commonly found in previous studies and this study that the blame is put on the patients' inability to understand and retain the information provided, instead of the HCPs considering that the information may not have been given in a form that could be understood by the patients.

Previous studies have also reported that patients' adherence often depends on how they feel physically, which may relate to their lack of understanding with regard to how their treatment and management work (Lawton, Parry, Peel, & Douglas, 2005; Williams et al., 2008). These studies further described that patients tend to stop their medication or neglect other areas of their management if they feel better or asymptomatic. Bhattacharya (2012), on the other hand, found that patients tend to neglect or ignore medically recommended lifestyle changes as they do not consider they will yield any positive outcomes with regard to their health conditions. This indicates that any decision as to whether or not to adhere to them (i.e. to stop or to self-adjust) was made based on the patients' beliefs and attitudes towards health and the healthcare system, along with their perceived benefits and risks, which were often conceptualised very broadly and were difficult for the patients themselves to verbally articulate (Nair et al., 2007; Williams et al., 2008; Mishra et al., 2011).

Similar practices and reasons were identified among the patients in this study, with the practice having been previously termed intentional non-adherence. PT8 (section 5.2), PT21 (subsection 5.2.2) and PT16 (subsection 5.2.4) were among the patients that either intentionally stopped taking or otherwise modified their medication when they did not consider it to be providing any significant benefit in terms of their current health condition and out of a concern about possible adverse side effects. This practice is in accordance with the concept of intentional non-adherence that was conceptualised by (Stack et al., 2010, p. 149) as *"... behaviour driven by a decision not to take medicine"*, whereas Brundisini, Vanstone, Hulan, DeJean and Giacomini (2015: p. 14) define it as *"... the patients' deliberate refusal to adhere to a specific medication regimen"*. In this study, these definitions of intentional non-adherence that refer to pharmacological modalities are extended to other forms of T2DM management, including non-pharmacological modalities.

Furthermore, as is illustrated in the accounts by HCP14 and PT12 in 4.3.3, the patients often opted to discontinue the medication without any other follow-up measures and reported this to their HCPs only at their next follow-up appointment.

As a result, some of the patients were unable to control their glycaemic levels and began to develop complications, as demonstrated by PT12 in 4.2.4. Comparable with findings by Gimenes and colleagues (2009), the patients in this study were seldom explicitly asked about their experience of medication side effects by the HCPs, in contrast to being asked about their adherence. This was found to be the case especially with regard to patients' oral medications as opposed to their insulin. The latter was usually enquired about by the diabetes educators at the hospital clinic, as they are the ones responsible for educating patients about insulin adjustment. This may be due to the serious side effects of insulin, especially hypoglycaemia, compared to other medications, with the latter not commonly leading to such life-threatening effects.

It also appeared in this current study that the HCPs were failing to pay sufficient attention to patients' concerns about developing side effects from their medication as they may have considered the potential to be exaggerated (Williams et al., 2008). In addition, Brundisini and colleagues (2015) reported a tendency for patients to take a trial-and-error approach to adjusting their medication as a result of this concern. They perceived patients' non-adherence to be related more to a lack of understanding, financial constraint or another motive, such as a preference for traditional medication. This current study suggests a slightly different finding, as the HCPs have begun to realise and address their patients' concerns regarding the impacts of the medication on their kidneys. Yet some of the patients still perceived that the issues were not being properly addressed, thus resulting in the same non-adherence. Nair and colleagues (2007) also found a lack of information received by patients on the benefits and risks of treatment or management to be another of the main reasons for patients' self-adjustment. A similar reason may also be the main factor for this practice among the patients in this study, especially given the nature of the information provided by the HCPs.

6.3.2 Patients holding the ultimate power through intentional non-compliance

As has been discussed previously, there are patients who nevertheless fail to adhere to their diabetes management despite having initially agreed to do so or not refusing the option that was identified. They may do this if they feel that it does not suit their needs and diabetic condition, or if they are concerned about the adverse effects of the management, especially with regard to taking their medication. However, patients were also found who intentionally did not comply with their management due to a perception that it had been paternalistically prescribed without their agreement and/or any further discussion. For this reason, the term non-compliance is used in this section in place of non-adherence, reflecting that the patients did not proceed with their prescribed treatment regimen as they perceived both a lack of discussion about it and that the decision had been made paternalistically (Horne, Weinman, Barber, & Elliott, 2005).

It can be argued that patients' intentional non-compliance is their way of exerting power, as asserted by Bradbury-Jones, Sambrook and Irvine (2008) and supported by Laverack (2005; p. 34), who stated *"... to exercise choice is the simplest form of power"*. Thus, some patients intentionally chose not to comply with the prescribed therapy as they perceived that a decision had been made without any prior discussion and consensus from their side. This demonstrates that they are attempting to reclaim the power to determine their own management that they had either been denied or did not exert during the time when the decision was made. Instead of voicing their disagreement with the prescription or advice of their HCPs, most of the patients preferred to express it through their own non-compliance. This is in accordance with an assertion made by Freire in his book *Pedagogy of the Oppressed* (1970). He stated that in some situations, the oppressed people (patients) tend to be the oppressors instead of finding ways to liberate themselves from their oppressed state. He added that this may happen as they view their oppressor (in this context HCPs) as their model of 'manhood'. However, there are certainly other factors associated with patients' intentional non-adherence/non-compliance, including their lack of confidence in the prescribed management, as mentioned by PT16 and in section 5.2.4

of the previous chapter, and their misconceptions concerning diabetes and the medication (Mann et al., 2009).

6.3.3 Patients' non-disclosure of their non-adherence and concern

Parallel to the report by Horne and colleagues (2005), non-adherence among the patients in this study remained relatively undisclosed. In the case of non-adherence, a similar hesitance and the reasons for patients' disclosure of any other information with their HCPs were found, as discussed throughout this chapter. Besides, it can be sensed that some patients did not share their non-adherence because they were embarrassed by their inability to comply or adhere to their management, whether or not this was intentional on their part. However, previous researchers have suggested that this may refer more to unintentional non-adherence and thus reflect the patients' inability to adhere to their management, with the potential reasons including forgetfulness, carelessness, poor manual dexterity, losing their medication, running out of supplies or an inability to afford the treatment (Horne, Mailey, Frost, & Lea, 2001; Gadkari & McHorney, 2012).

This embarrassment, which can also exist as shame and self-consciousness, may develop into frustration or anger when patients are confronted about their non-adherence or uncontrolled glycaemic level, since, aside from indicating their poor health, it can also point to moral failing and render them vulnerable to stigmatisation by their HCPs, friends and families (Broom & Whittaker, 2004; Archer, 2014). These emotions can be identified in PT22's account as presented in 5.2.1. The embarrassment and frustration can be sensed in her account when she was asked by her HCP to manage her weight better. In addition, Archer (2014) noted that for patients who shared a non-adherence that could be linked to their uncontrolled glycaemic level, their embarrassment could be identified in their expression of a sense of inadequacy, self-deprecating tones and their body language. Fink and Walker (1977), on the other hand, suggested that humorous responses are commonly used in an embarrassing interaction, especially among individuals of relatively equal status. This occurrence may be more significant in the Malaysian high-context

culture where non-verbal communication commonly carries more meaning compared to verbal communication. This may not be explicit in any of the participants' accounts presented in the previous Findings chapter, but my notes gathered during the data collection period do convey this sense among the patients as they often described their non-adherence humorously during the interview.

Patients' embarrassment at their non-adherence to their T2DM management comes in addition to their embarrassment at their diagnosis of the T2DM itself (Archer, 2014). Both of these can be detrimental to the effort to preserve their quality of life. In dealing with patients' embarrassment during their clinical encounter, the HCPs in a study by Zoffmann and colleagues (2008) were found to frequently reflect on the issues they perceived as contributing to the embarrassment felt by patients when sharing by themselves without being directly asked to do so. This was done by gathering indirect information related to the issue so that they could make their own deduction, which was also identified in the present study where certain HCPs made assumptions with regard to their patients' non-compliance or non-adherence. However, Zoffmann and colleagues (2008) questioned the reliability of this practice as no confirmation or verification of the deductions was sought from the patients by the HCPs; there may thus have been misassumptions made by the HCPs. Furthermore, Archer (2014) suggests that HCPs must remain professional in communicating with their patients, including in investigating their non-adherence and other issues that patients may find embarrassing. In order to achieve this, HCPs should avoid sarcasm, teasing, pity and condescension, all of which can aggravate a patient's sense of shame. Archer also emphasises that the body language used by HCPs is imperative as self-conscious patients are usually sensitive to things such as a frown, stare or glance away, which they often associate with contempt. Besides, HCPs are also advised to be authentic, including about have feelings of shame, and to ensure that patients feel safe, secure and confident to share any embarrassing issues (Archer, 2014). This can be achieved if patients are aware that a certain degree of flexibility is common in managing chronic illnesses and they know it is possible to take a more realistic goal that may better suit their needs (C. R. Rogers, 2004). As presented in 5.3.2, these HCPs' facilitative attitudes and practices were found to

make the patients feel more respected and comfortable in sharing their side of the story.

Conversely, the finding presented in 5.2.4 reveals that some of the patients tried to conceal their prolonged between-appointment non-adherence from their HCPs by only adhering to the medication and then fasting during the run-up to their follow-up appointment or blood test. These practices were usually carried out not only to hide their embarrassment at not being able to adhere to the T2DM management but also for them to be viewed as a good patient, which they believed would help to maintain their good relationship with their HCPs. A similar reason may also account for their hesitance to share their disagreement with the HCPs' recommended option. Archer (2014) suggests that this non-sharing by patients in order to be viewed as a good patient may result from HCPs' common practice of tending to praise patients with good glycaemic levels as doing a good job of controlling their T2DM, which also commonly appeared in Chapters 4 and 5. Archer refers to such practice as 'benign paternalistic statements', which can also serve as an expression of HCPs' enjoyment at having patients who are able to fulfil the notion of the 'ideal diabetic'. A study by Renfrew and colleagues (2013) among Cambodian patients reported that the patients wished to please their HCPs and not disappoint them. Some of the patients in this present study also described the practice of concealing their non-adherence as it was expected that the HCPs, especially the physicians, would be angry if they knew the actual situation. This resonates with the assertion by Raven (2008) that patients tend to hide their non-adherence if they feel they have been forced to agree to and carry out the treatment, and they expect some form of punishment further down the line. As a result, misinformation or a lack of shared information during the clinical encounter is inevitable and may become a major barrier to care (Renfrew et al., 2013).

In addition, extending from the previous discussion on patients' tendency to not adhere to their newly prescribed treatment or management as they did not believe it to be necessary, some of the patients in this study did not share their intentional non-

adherence for the same reason. This may relate to a denial of the severity of their T2DM on their part, or to their inability to appreciate it as something that they needed to discuss with their HCPs. However, at the point at which they begin to realise that it is important and try to share it with the HCPs, the HCPs most probably treat it as an excuse by the patients to refuse the new prescription or advice, as was identified in the account by HCP13 in subsections 4.2.3 and 5.2.1.

All of the findings discussed in relation to patients' non-adherence are comparable with those from the study by Nair and colleagues (2007) in the sense that the decision-making among some of the patients in this present study continued even after their clinical encounter, via their own experimenting with and testing the prescribed or recommended treatment and management. Overall, the discussion in this section illustrates the shortcomings of HCPs' paternalistic approaches and the lack of patient involvement in T2DM management decisions. This reflects the importance of a collaborative effort between patients and HCPs as the management of T2DM among the patients in this study involves self-management. In improving adherence among patients, DiMatteo and colleagues (2012) suggest three important clinical actions, as follows: (1) ensuring that patients have the right information and understand how to adhere – including listening to their concerns and encouraging their participation in decision-making; (2) helping patients to believe in their treatment and motivating them to carry it out by addressing the cognitive, social, cultural, normative and contextual factors which are known to have an effect on their beliefs, attitudes and motivation, and (3) assisting patients to overcome practical barriers to treatment adherence and develop a workable strategy for long-term disease management. All of these suggestions can be related to the shared decision-making approach.

6.4 Interpersonal relationship and communication

In comparison to decision-making for acute conditions, previous scholars have suggested that patient involvement in decision-making for a chronic condition should be extended from merely selecting the treatment option that is best suited to the

patient (Montori et al., 2006; Sepucha & Mully Jr, 2009). Instead, in this study context, parallel with symbolic interactionism that highlights how the meaning of the practice is socially constructed (Blumer, 1969), the main challenge lies in its implementation, where integral roles are played by both the patient–HCP interpersonal relationship and communication.

In this study, the communication skills deemed important for HCPs to have include providing information, facilitating two-way interaction with patients by asking them questions to elicit information, and listening attentively and responding to patients' complaints and answers. The findings presented and earlier discussions have indicated that these skills cover both verbal and non-verbal communication, which is consistent with the Malaysian high-context culture. Furthermore, similar to an assertion by Larson and Xin Yao (2005), the participants in this study also emphasise the importance of HCPs' personal engagement and empathy with patients, which seemed to be lacking among the HCPs in this present study. The patients in this current study were often hesitant to become involved in the encounter as they were worried about being reprimanded by their HCPs. This perception most likely derived from previous negative experiences in their efforts to engage with HCPs. Besides, HCPs' threatening way of communicating the information acted to further hinder patient involvement. In accordance with this, Larson and Xin Yao (2005) posit that the development of HCPs' emotional and cognitive empathic skills in communicating with their patients may improve two-way interaction in discussing the decisions. Nonetheless, the findings presented in Chapter 4 and section 5.2, together with the discussion in 6.2.2.2 on HCPs' lack of consideration of the information shared by patients, may indicate the importance of patients' own communication skills when it comes to them presenting their problems, needs, preferences and values.

In addition, it was found that other factors influenced both the interpersonal communication and relationship between patients and HCPs, including the continuity of the relationship and both sides' trust in each other. The effects of these factors

were demonstrated by the hesitance among many of the patients to answer HCPs' questions and to be open to sharing their preferences or concerns with HCPs whom they had just met or with whom they were not comfortable. Similarly, despite patients' willingness to communicate with their HCPs, some of the HCPs ignored the patients' efforts as they did not trust them, which was especially the case for patients who they were meeting for the first time. As presented in Chapter 5, many of the participants perceived continuous and ongoing patient–HCP engagement as being necessary for the development of a good interpersonal relationship, which they referred to as good rapport between them that tended to enhance the trust that they placed in each other. However, in this study context, the patients attend public health facilities where there is only a very slim chance of them meeting the same HCPs repeatedly, especially the same medical officers. Besides, similar to the findings of a study in Australia by Smith, Dixon, Trevena, Nutbeam and McCaffery (2009), the patients in this study also emphasised that an ongoing relationship would not ameliorate their involvement during the clinical encounter if they did not perceive the HCPs' approaches as suiting their involvement or if they did not feel comfortable with their HCPs, as was seen in section 5.3.

All of the findings discussed in this section support the broader conceptualisation of shared decision-making as it is emphasised by Entwistle and Watt (2006). They highlight the incorporation of the relational aspect of patient involvement. Comparable with the findings of this present study, Entwistle and Watt (2006) acknowledge the patients' and HCPs' subjective experience of involvement in terms of their feelings and views about each other as a crucial variable, regardless of what they say and do during the actual decision-making. In addition, the overall findings of this present study indicate that the interpersonal relationship is linked bi-directionally with how the parties communicate with each other during the decision-making, which then influences the extent to which the patient is involved in the decision.

Besides, the findings of this present study are consistent with the theory of interpersonal relations by Peplau (1997) that describes the relationships between patients and their HCPs as being dynamic, interactive and a relational process that develops over time. This theory has recently gained in popularity following its use by a number of other scholars in exploring and explaining patient involvement in decision-making practice (D'Antonio, Beeber, Sills, & Naegle, 2014; Mahone, Maphis, & Snow, 2016; Hochberger & Lingham, 2017). Generally speaking, the interpersonal relationship between patients and their HCPs influences the quality of the care provided that is intended to improve patients' well-being and reduce their dependency. However, in accordance with Morgan and Yoder's (2012) argument, the findings of this present study also indicate that the patient–HCP interpersonal relationship may not necessarily indicate that the patient is involved in the decision as the relationship may be asymmetrical. This is because the traditional descriptions of the interpersonal relationship often refer to it as one in which HCPs hold the authority, power and control over their patients (Peplau, 1997; Leplege et al., 2007). Thus, similar to the findings of this present study, Van Der Cingel and colleagues (2016) emphasise that patient involvement in their own care can only occur if HCPs adopt facilitative values such as empathy, trust and respect for the balance of power within the relationship.

6.4.1 Trust

The previous discussion about this interpersonal relationship corresponds to the assertion by Mechanic and Schlesinger (1996) as both the patients and HCPs in this study admitted that long-term engagement, together with having a trusting therapeutic relationship, tended to facilitate the decision to be shared. Trust is one of the central attributes of the interpersonal relationship that is found to enable patient involvement throughout the decision-making process in this study as it facilitates honest conversation between patients and HCPs. A similar assertion was made by Pellegrini (2017) that trust is the keystone which can make or break a patient–HCP relationship. However, the findings of this study also demonstrate that the association between trust and patient involvement in the decision is not linear and intricate.

6.4.1.1 Patients' trust

Even though a good long-term relationship may increase the level of trust on both sides, other factors also seem to have an influence on the degree of trust that the parties place in each other. Aligned with Bourdieu's assertion, patients carrying bad experiences from a past encounter with their HCPs were found to lack trust in their HCPs, which then shapes their involvement in the decisions. Such experiences include being ignored or not being heard or treated well by the HCPs, a lack of consideration of their preferences and/or a feeling of being cheated by the HCPs and feeling that the decision taken was not suitable for their needs and condition. All of these experiences are associated with HCPs' verbal and non-verbal communication skills, which Pellegrini (2017: p. 96) cites as being *"… a vehicle to build trust"*. Riva and colleagues (2014) also found HCPs' communication skills to be among the most important features affecting patients' trust. The above discussion provides further illustration of the complex, nonlinear and multidirectional linkages between the patient–HCP relationship, communication and trust in patient involvement in decisions.

A review by H.H. Choy and Aniza (2017) on the aspect of trust in the healthcare field suggests a diminishing level of trust among patients towards their HCPs in both the Western and Eastern worlds. Similarly, in this study, there were patients who did not fully trust their HCPs, which subsequently influenced their level of involvement in decisions. Interestingly, a lack of patient trust can lead to patients playing two different roles, namely those of active and passive. Some patients felt compelled and empowered to take the responsibility to decide for themselves as they did not trust their HCPs to make a decision that best suited them or otherwise considered that they themselves were better educated about their condition. On the other hand, some patients' lack of trust in their HCPs made them more passive as they did not see the benefit of becoming involved. However, these patients would usually go on to make their own decisions based on their concerns, preferences and values that were not disclosed when the decision was made by their HCPs. This practice of non-adherence

can serve as an indicator of patients' implicit way of reclaiming the power to decide as they had not been able to exercise this power during their clinical encounter.

Discussion was held with regard to how patients' limited scope for meeting with the same HCPs, especially the same physician, served to inhibit the development of a trusting interpersonal relationship. However, Pearson and Raeke (2000) suggest there is another type of trust, aside from interpersonal trust, that exists in patient–HCP relationships, namely that of social trust. This can be defined as trust in collective healthcare institutions and is closely related to general social confidence in the institutions themselves (Pearson & Raeke, 2000). The level of social trust that patients place in healthcare institutions usually extends to HCPs as the members of those institutions. Thus, some of the patients in this study who did not meet the same HCPs put their social trust in their HCPs based on the notion that as experts in the institution, they would do their best to make them feel better. According to research by Riva and colleagues (2014), patients, seeing HCPs as the experts, trust their knowledge, expertise and ability to identify their problems and provide treatment. Added to this, HCPs' positive attitudes in showing empathy and interest with regard to patients' sharing meant there were also some patients who responded positively to their HCPs' enquiry and became actively involved in making a decision during their encounter, as they believed that their input mattered.

On the other hand, there were also patients in this current study who trusted their HCPs and who preferred for them to make the decision on their behalf. This was similar to the patients in a study in Australia by D. Y. L. Lee, Armour and Krass (2007), where, despite a few of the patients being concerned that they were not receiving enough information, they mainly relied on their HCPs to make a decision and accepted that decision without question due to the trust and respect that they placed in them as experts in the healthcare system. Thom and Campbell (1997) further suggested that patients' adherence to their trusted HCPs' recommended treatment was usually facilitated by the HCPs' personal traits of being compassionate, understanding and honest in communicating with patients. Fernandez, Seligman,

Quan, Stern, & Jacobs (2012) found this facilitation to be associated with an increase in patients' ability to achieve better glycaemic control.

However, patients' unquestioning trust in their HCPs had led to them experiencing feelings of distrust. This has been commonly identified among patients who have felt cheated after discovering that the decision made for them by the HCPs had actually led to a worsening of their condition, or if they had later found out about another option that they felt would better suit their condition but about which they had not been informed by the HCPs. Patients place their trust in their HCPs from the outset in the belief or expectation that the HCPs will behave in such a way that will benefit them, or at least not cause them harm, and this includes deciding what is best for them (W A Rogers, 2002; Thom et al., 2011). W. A. Rogers (2002) further explains that this belief and expectation comprises both emotional and cognitive elements, with power also often involved. Power is usually accorded to the trusted side, which in this context involves the power to decide for the patients. As such, this finding is understandable as the patients come to feel that their trust has been violated. The consequences of this loss of belief in HCPs with regard to their involvement in the decision were similar, if not worse, to those seen in the aforementioned patients who lacked trust in their HCPs from the outset. Despite the fact that some patients' distrust and lack of trust actually had a positive effect in terms of it increasing their sense of empowerment to be involved in decisions regarding their care, such situations of distrust should be managed or prevented due to their potentially greater negative impacts, including non-adherence, dissatisfaction and impaired general well-being among patients (Bauer et al., 2014).

As such, Pellegrini (2017) advises that HCPs make efforts to build trusting relationships with their patients and to not exploit patients' trust and vulnerability in order to avoid such negative repercussions. In doing so, patients should be treated as people, and their expertise in terms of their needs, preferences and values should be both elicited and respected (Peek et al., 2013). Despite being entrusted with the power to make decisions on behalf of their patients, HCPs should communicate

related information honestly and ensure patients understand the information being presented and any decision that is made.

6.4.1.2 HCPs' trust

Besides patients' trust in their HCPs, the findings of this study have also highlighted the noteworthy relationship between HCPs' trust in their patients and patient involvement in decisions. It appears in this study that HCPs' trust in patients is reciprocated with the disclosure of information by patients due to the trust that they place in their HCPs and the patients' sense of empowerment to be involved in the decisions. Supporting the assertion of W. A. Rogers (2002), this finding comes despite the fact that patients sit on the more vulnerable side within a patient–HCP relationship in the healthcare field. W. A. Rogers (1999) also argues that HCPs' trust in their patients enriches the concept of beneficence rather than diminishes it as it combines patients' expertise with that of HCPs, which further leads to HCPs having greater therapeutic power as the chosen treatment is the best fit for the patients. Besides, as presented in both of the Findings chapters, those HCPs who trusted their patients were found to be more encouraging and to welcome their patients' involvement and thus were more likely to share the responsibility and power for deciding with them. This constitutes a significant contribution to the limited existing literature on HCPs' trust in the area of patient involvement in T2DM decisions, as presented in Chapter 2. It was highlighted there that most studies have tended to focus more on patients' trust in their HCPs despite the fact that the patient–HCP relationship is bi-directional in nature.

In an ideal patient–HCP relationship, the HCP trusts a patient's motive, testimony and competency to decide (W. A. Rogers, 2002). The lack of HCPs' trust in this study was often due to their perception of being deceived by the patients as they were deemed to not be telling the truth and/or withholding information, which was also demonstrated in the review by Wilk and Platt (2016) on this matter. Even though this might be true, as previously discussed in 6.4.1, some patients chose not to share information owing to their immense trust in their HCPs' expertise, their own

forgetfulness, not knowing which pieces of information were important to be shared, or due to not wanting to be considered as difficult; as such, the lack of sharing was not merely because the patients wanted to conceal the information.

Besides, in this study, the HCPs' trust in the patients was further compromised by the patients' poor glycaemic control and progress with their T2DM. This is in line with the assertion that HCPs place their trust appropriately in their patients if the patients themselves fulfil their obligation to adhere to their management, which is usually demonstrated in an improvement of their T2DM status (Hawley, 2015). A lack of HCPs' trust in their patients was found to damage patients' opportunity to be involved in the discussion about decisions on their care. This is because the lack of trust is usually translated in the HCPs' paternalistic practice, including deciding for patients, withholding options and information and ignoring patients' concerns, preferences and values. This will most likely further affect patients' trust in them, which then leads to patients becoming reluctant to disclose important information and ultimately to further non-adherence.

The findings on HCPs' trust in the patient extend the understanding of the dynamic of trust within a patient–HCP relationship. This discussion on its effects on the practice of both HCPs and patients addresses the concern raised by Wilk and Platt (2016) regarding the lack of exploration in this matter. It is also aligned with shared decision-making as the discussion on trust in this study deviates from the previous main focus on patients as being passive receivers who are situated on the less powerful side within the relationship. The findings of this study further indicate that in enabling patient involvement in decision-making, not only do HCPs need to gain and maintain patients' trust, but patients are also equally responsible for doing the same with regard to the trust of their HCPs.

6.5 Perceived role of HCPs and patients

The findings of this study highlight the participants' perception of the roles of the patient and HCP as being one of the main factors that hinder patient involvement in decision-making.

6.5.1 The role of the HCPs

The decisions on patients' T2DM care in this study were generally made based on the traditional biomedical model, with this being demonstrated in two main ways. Firstly, the main focus in deciding patient care is to achieve a better clinical outcome. In doing so, it was illustrated in Chapter 4 that the HCPs commonly make the recommendations and, on some occasions, make the decision for patients based on the Malaysian CPGs for managing T2DM. However, based on the discussion of the CPGs, despite mentioning patients' input and involvement in certain areas of T2DM management, it appeared that there is still a lack of emphasis on patient involvement in the decisions and on ways in which to involve patients. This can serve as one of the reasons for HCPs' adoption of the biomedical model instead of patient-centred care in managing their T2DM patients. A study by Guerrier and colleagues (2013) lends support to this assertion as they found that HCPs' intention to engage their patients in shared decision-making was negatively influenced by their intention to follow the CPGs. Secondly, the findings suggest that limited patient involvement in the process is due to the paternalistic belief, value and attitude. These include beliefs that the HCPs are the main decision makers, a lack of value accorded to patients' disease experience, and patients' dependence on their HCPs, including in determining the issues that need to be addressed at each follow-up appointment.

All of the above discussions of the findings are in accordance with the traditional descriptions of professionalism or the profession of the HCPs. In addition to Freidson's (1971) description of HCPs' authority in the clinical encounter that was presented in Chapter 2 (section 2.2), Parsons (1954) defines a profession as *"... a cluster of occupational roles, that is, roles in which the incumbents perform certain functions valued in the society in general"* (p. 372). In addition, WHO also states that

the general role of HCPs is to improve the quality of health of the population by delivering important services or information in order to promote health, prevent diseases and their complications and provide healthcare services (WHO, n.d.). If the ethical principles of beneficence and non-maleficence of HCPs are added to this, HCPs are considered to be the guardians of patients, responsible for ensuring their safety and that they are provided with the best care, as determined by the HCPs based on their knowledge, values and expertise (Emanuel & Emanuel, 1992; Stubblefield & Mutha, 2002). The dominant role of HCPs in clinical encounters, particularly that of physicians, is also supported by the sick role concept by Parsons (1951b), which is discussed next in subsection 6.5.2. The relief of patients from both their normal everyday roles and subsequently from their sick roles so that they can return to their normal everyday roles usually requires legitimation from physicians. Thus, the power and paternalistic approaches of the HCPs which are aligned with the biomedical model, especially those of the physicians, are unquestionably accepted and considered to be common by the society (Freidson, 1971).

However, as discussed previously in both Chapter 2 (section 2.2) and in this chapter (section 6.4), the dominance of HCPs over patients is no longer accepted without question. Consequently, the traditional descriptions of professionalism in medicine and healthcare have started to be challenged. Alongside the old, yet still relevant, components related to HCPs' altruism, technical expertise and competency, more recent descriptions of professionalism have started to include elements such as respecting patients' autonomy, good interpersonal relationships and communication skills (Irvine, 2001; Priest, 2011). These extra elements have been incorporated into The Code of Conduct among HCPs in Malaysia, as presented in Chapter 1. Ultimately, a more contemporary style of patient-centred care, particularly shared decision-making, may better suit the changing healthcare landscape in order that patients can actively contribute to their health management, combined with guidance from their HCPs, to ensure their safety.

6.5.1.1 HCPs' dilemma

In accordance with the changing healthcare landscape, a large proportion of the participants in this study, including the HCPs, believed it was important for decisions regarding patients' management to be shared among HCPs and patients. The HCPs had a more realistic as opposed to idealistic standpoint in terms of realising that the most suitable option for the patient may not necessarily be the one that comes out on top based on the CPGs. However, a belief in the importance of shared decisions, combined with their preconceived ideas regarding their expected professional roles, seemed to leave most of these HCPs in an ethical dilemma as to the extent to which the patient should be involved in decision-making, which is similar to the findings of a study by Shortus and colleagues (2011) and a more recent study by Entwistle and colleagues (2018). Comparable with the findings by Shortus and colleagues (2011), the HCPs in this present study showed a range of practices in terms of facing the conflict of balancing these two competing professional responsibilities. As suggested by Shortus and colleagues (2011), the HCPs who placed a higher value on patient involvement tended to be more receptive to the patients' complaints, preferences and values compared to those HCPs who were strongly motivated by the principle of beneficence over patient autonomy. The latter type of HCPs tended to be more assertive and persuasive in ensuring that their patients received the best possible care, according to their consideration.

Cohen (2013) further suggested that persuasion, which he referred to as nudging, is especially common among HCPs who have limited knowledge and skills in relation to involving their patients in making a decision. Similarly, the limited knowledge and skills among some of the HCPs in this current study also resulted in their unintentional paternalistic attitude. These HCPs admitted that they preferred for decisions to be made together with their patients, while some were of the belief that they already practised shared decision-making. However, other descriptions of how decisions were made during their encounters with patients were a better fit with the paternalistic and biomedical model of care. This is similar to the findings of a study by Claramita and colleagues (2013), where it was found that paternalistic behaviours

among HCPs were due to a lack of time and HCPs' belief that patients were unprepared for a more participatory style. These reasons can also be identified in this current study.

The HCPs' dilemma in considering patient involvement when making decisions in this study was further magnified by restrictions on the resources available in their publicly funded healthcare system, as argued by Sculpher, Gafni, and Watt (2002). HCPs must balance the need of one individual patient for a type of treatment available in only limited supply against the needs of all other potential patients who urgently require the same treatment. Besides, it is common for effective treatments that fail to meet the requirement of being cost-effective to not be available in these facilities, thereby further limiting the treatment options. However, realising the great benefits of involving patients in making decisions, Sculpher and colleagues (2002) suggest some further potential solutions to help HCPs practise shared decision-making in public healthcare facilities. These include 1) informing patients only about the cost-effective options that are available in their facilities; 2) using the shared decision-making process to determine whether a treatment is cost-effective, and 3) distinguishing 'clinical' from 'system' guidelines (Sculpher et al., 2002). The findings of this study demonstrate that some of the HCPs already practise the first two of these suggestions, although not without issues. Informing patients only of the options that are available at the facilities may reduce their trust as they may have separate access to information about other, less cost-effective options from other sources, thus leading to a situation in which patients' agreement is less likely to be obtained (Sculpher et al., 2002), which was also found in this present study.

6.5.2 The role of the patients

In the previous subsection 6.4.1.1, it was mentioned that the belief in HCPs having greater responsibility for reaching medical and health decisions in comparison to that of patients often resulted in the patients taking a more subservient role. This is further strengthened by the traditional belief regarding the patients' role in making a decision, which was found to be common among the participants. As the person

seeking help, the patient has always been viewed as the one who should cooperate and comply with the HCP; as such, the patient will tend not to share their concerns without explicit invitation or encouragement from the HCPs. Patients are typically reluctant to ask questions or share preferences based on their experience, and they would probably hesitate to express disagreement during the decision-making process. These findings can be associated with the sick role theory by Parsons (1951b), where being sick is considered to be a role. As such, various expectations are placed on patients. According to Parsons (1951b), as a sick person, the patient is entitled to be relieved of their normal everyday role and needs to seek medical help to enable their recovery, which will usually require them to comply with the medical prescriptions and management as laid out by their HCP. The applicability of this concept to understanding the passive role played by patients due to the social forces that shape paternalistic medical and health encounters in this study is similar to the findings of a study by Fahy and Smith (1999).

However, the sick role in chronic illnesses, including in T2DM, is more complex than that described by Parsons (Varul, 2010). Parsons' description of the obligation of patients to not perform any other roles in fulfilling their sick role, including making a decision, along with HCPs' medical authority due to their exclusive expert knowledge, seems to fit with the descriptions given by some of the participants in this study, despite their belief that T2DM patients are responsible for carrying out their own self-management when they are out of the healthcare system. However, Varul (2010) further suggests that the lack of patient involvement in decision-making tends to negatively impact patients' self-esteem in general. This may further complicate the management of T2DM patients, with Swendeman, Ingram, and Rotheram-Borus (2009) having found that low self-esteem may reduce patients' ability to self-manage. (Charmaz, 2000) also emphasised that one of the ways to improve patients' self-esteem is through participation in any activities that involve reciprocity, including involvement in medical encounters.

On the other hand, compared to the temporary sick role in acute illness where a patient will recover and no longer have to fulfil the role of a sick person, T2DM is a chronic, lifelong illness. Thus, T2DM patients are compelled to fulfil both their normal everyday role and their sick role. In fulfilling their normal role, it is common for such patients to accumulate T2DM-related medical knowledge, skills and experiences which serve to erode the aforementioned HCPs' medical expertise and authority (Varul, 2010). This may result in resistance and dissatisfaction among patients, especially in settings where belief in the sick role concept remains strong, including in the settings of this study (Claramita et al., 2013). Nevertheless, as discussed previously, the majority of the patients in this study did not explicitly indicate their dissatisfaction and disagreement and behaved in a subserviently passive manner during clinical encounters. These passive behaviours commonly resulted from the feeling among some patients that their active involvement in decision-making may irritate their HCPs, in addition to such behaviour having been previously ignored by their HCPs. This was considered by Claramita and colleagues (2013) to fit the Asian cultural pattern in which HCPs are located higher up in, and thus dominate, the healthcare system. However, Claramita and colleagues (2013) also found that patients' implicit dissatisfaction and disagreement were rarely adequately recognised by HCPs. This can further complicate efforts to identify the most suitable option that can be carried out by patients and often results in dissatisfaction and non-adherence among patients, which was clearly demonstrated in this study.

6.5.2.1 Patients' preferred role in being involved

When discussing the separate roles in shared decision-making, Chapter 2 presented the patients' preferred role as one of the more popular areas for research. Based on this study, besides patients' trust in their HCPs and their ignorance of their health condition, their perception of their sick role appeared to also be a reason for their preferred passive role in making the decision. This is comparable with previous studies in the area which also found that sicker patients prefer to take a more passive role (Stiggelbout & Kiebert, 1997; Levinson et al., 2005). This finding lends support

to the debate around whether or not the patient's preference to remain inactive in decision-making is followed (Davies & Elwyn, 2008; Stiggelbout et al., 2012; Kehl et al., 2015). Most of the above-mentioned scholars highlight the importance of respecting patients' preference to play a passive role. However, the link found in this study between patients' preferred and actual roles of not being active in making the decision and their perception of the sick role supports a suggestion by Stiggelbout and colleagues (2012). The latter authors suggest that the genuine preference of patients with respect to their role in decision-making should be respected. However, they also highlight that all patients should be empathically invited and sufficiently supported by their HCPs in order to be actively involved. This is in addition to their other suggestion that patients' preferred role should be explored once all of the relevant information has been provided.

6.6 Power relations in decision-making

6.6.1 Power dynamic between patients and HCPs

The findings of this study demonstrate that patient involvement in decision-making revolves around the power dynamic between the patient and HCP, and that the Malaysian culture and social system also extend to the country's healthcare system. Involving patients in their T2DM management decisions requires a sharing of power and responsibility between HCPs and patients (Hook, 2006). However, from the discussion of the findings, it can be established that the patient–HCP power dynamic in decision-making in this study currently leans towards the HCPs, despite both parties being open to the idea of patient-centred care and patient involvement in decision-making. This is generally shown by the authority of the HCPs in decision-making on behalf of their patients during the clinical encounters. Based on Lukes' (2005) book *Power: A Radical View*, in which he draws upon Dahl (1957) and Bachrach and Baratz (1970), power can be present in three ways: overt, covert and latent power. The HCPs in this study were found to exercise all three forms of power in ensuring that their patients received what they considered to be the best treatment or management, and this extended throughout the clinical encounter, from agenda setting to preference shaping and to the decision-making itself. As presented in

Chapter 4, there were instances where HCPs decided for their patients without discussion, with or agreement from their patients, and also examples of HCPs using intimidating messages to coerce or persuade the patients to accept their recommendations. These approaches by HCPs are identified as overt power according to Lukes (2005). In this present study, patients' perception of the use of overt power by HCPs was often found to lead to their ignorance as to the decisions being made, greater passivity and undisclosed disagreement, dissatisfaction and non-compliance. Realising this, there were instances in which the HCPs did not share certain information in order to shape their patients' perception, cognition and preference. This indicates that HCPs covertly use their power so that patients will voluntarily agree with their recommended care and thus avoid conflict. Nonetheless, the findings of this study have also demonstrated that this might raise doubts among patients towards their HCPs, especially when they have acquired the information from elsewhere, as previously mentioned in section 6.2.2.1. Both of these types of power occur at the individual level; that is, they are exerted by the HCPs towards the patients (Lorenzi & Lukes, 2006).

In addition, however, a more insidious form of power is identified in this study. This type of power is what Lorenzi and Lukes (2006: p. 91) consider as the *"outcome of socially structured and culturally patterned collective behaviour"* and is known as latent power. It may also be referred to as Pierre Bourdieu's (1991: p. 23) symbolic power, where *"... the power is seldom exercised as overt physical force: instead, it is transmuted into a symbolic form, and thereby 'recognized' as legitimate"*. The findings that are particularly relevant to this form of power are the dominance of the HCPs' focus according to the biomedical model when determining the problems that need to be addressed, the accordance of a higher value to HCPs' technical knowledge over patients' experiential knowledge, HCPs' higher positioning within the healthcare system hierarchy and the embodiment of the traditional patient sick role by patients and HCPs in making health decisions. All of these perceptions, beliefs and values in the healthcare field are found to hinder the patients' intention and opportunity to be involved in decisions as they serve to strengthen the idea that the health decisions are the responsibility of the HCPs and that the patients' task is to

merely accept and carry out the decisions. This also indicates the relationship between Lukes' formulation of power and Bourdieu's conception of habitus, field and capital, which considerably shape the practice of patient involvement in decision-making. Since latent power is socially and culturally constructed, it is something that is already there, and it exists whether or not the HCPs wish to use it, or even if they did not intentionally want to use it. Further discussion on power based on Bourdieu's work can be found in the following subsections.

On the other hand, power has also been found to be used by the patients in this study, whether intentionally or unintentionally. This may be in the form of overt power, whereby some of the patients verbalise their disagreement with their HCPs' recommendation or else enquire about other options. However, this usually led to the HCPs' further use of overt and/or covert power to ensure the patients agreed with and followed their recommendations, especially in cases that featured a worsening of the patients' biomedical status. From Bourdieu's sociological stance, this finding can serve as an indicator that the patients' cultural health capital was undermined by that of the HCPs, which is generally due to the latter's higher position in the healthcare field (Bourdieu, 1986, Shim et al., 2010).

However, covert power was more commonly detected among the patients as they did not always carry out or modify their HCPs' prescribed or advised management, with this not being commonly disclosed to their HCPs. In accordance with Foucault's (1978) assertion, these findings indicate that the exertion of power among patients and HCPs in this study is intentional and calculated as it is done with an aim, compared to the latent or symbolic power that is already possessed by the HCP in a patient–HCP relationship (Bourdieu, 1991; Lukes, 2005). However, based on Bourdieu's (1998: p. 80) assertion, it could also be argued that the patient is being strategic in terms of them having their care matched with their needs, preferences and values, but this may be done without conscious calculation as they might be 'absorbed in their affairs' and therefore not cognitively consider its consequences.

Finally, it can be concluded that the ultimate power for making the decision in this study lies in the hands of the patients due to the fact that the management of T2DM extends beyond the patient–HCP encounter. However, the findings of this present study indicate that such an exertion of power by patients is not merely because they wish to seize the power to decide from the HCPs but rather in order to use it as a way of making their concerns and preferences heard by the HCPs, in addition to ensuring that their management suits their needs and values. The discussion on the power that exists in this study is related to decision-making activities and indicates that it is fluid and dynamic. Parallel to a proposition by Foucault (1978), patients' resistance to HCPs' power is found to be common. Power can also shift from one side to the other, with or without either party noticing that a shift has taken place. However, as the power possessed by the patients was not generally acknowledged as being comparable to the power held by the HCPs, their involvement in making the decisions during the clinical encounter was generally hindered.

6.6.2 Patient power and empowerment and HCPs' support

Patient involvement in making the decisions in this study has been found to be bi-directionally associated with patient empowerment in the sense that it does not only facilitate or hinder their involvement, but their experience of involvement in their decision and care can also strengthen or weaken their sense of empowerment. This association accords with Paulo Freire's (1970) view on empowerment as being both a process and an outcome. In the context of the current study, this is demonstrated by the way in which patients' sense of empowerment is one of the main drivers for them to become involved in decision-making and how this involvement can further develop patient empowerment.

The findings in Chapter 5 indicate that whether the patients' sense of empowerment stemmed from within themselves or from their HCPs' facilitating attitude and practice, it was developed based on a realisation of the importance of their role in managing their own T2DM. However, the discussion in 5.2.1 showed that the involvement of these empowered patients depended on their HCPs' permission and

their own acceptance of their HCPs. This dependency may complicate the effort of both empowered patients and HCPs to further empower the patients to be involved. One of the main reasons for this may relate back to how the HCPs understand patient empowerment in decision-making. According to most of the HCPs in this study, empowerment is limited to patients' adherence to their self-management. However, this understanding does not necessarily fully represent the concept of patient empowerment in shared decision-making as it only partially covers the description by Anderson and Funnell (2010: p. 277) of patient empowerment in diabetes care as *"... a process designed to facilitate self-directed behaviour change"*. This definition outlines the responsibility of HCPs to ensure patients understand their diabetes self-management and are aware of the aspects of their personal lives. The HCPs in this study have been shown to realise this, with many of them indicating that they try to impart as much information as their patients can handle, especially with regard to the information they consider to be essential to the facilitating of patient self-management.

Furthermore, Anderson and Funnell (2010) include patients' skill to think critically and make the decision about their management, especially in their day-to-day life, as the other half of patient empowerment. Nevertheless, they do not include it as one of the skills to be facilitated by HCPs, which resonates with the fact that only a few of the HCPs in this study mentioned this. Aside from the possibility of them not seeing this as a skill needed by patients, it may also have been the case that the HCPs considered the decisions taken by patients outside the clinical encounter to be out of their control, thereby making them the patients' responsibility and not theirs. This is contrary to the assertion by Ocloo and Matthews (2016) that HCPs could actually help their patients to develop their critical thinking, reasoning and decision-making skills by actively involving and discussing the options and decisions during the clinical encounter. Besides, the benefit of patients' critical thinking may go beyond the decisions to be made during the clinical encounter by, for example, helping patients to identify the information that needs to be shared. Besides, despite knowledge and awareness being crucial to the development of these skills, they both require the HCPs to have different sets of skills. However, there was a lack of

discussion on critical thinking among patients found in the current literature on shared decision-making, thereby supporting Ocloo and Matthews' (2016) point that the current models of patient-centred care are too narrow and require broadening.

The excerpt by PT22 in 5.2.1 also illustrated the struggle experienced by empowered patients to be involved in their decision. The patient verbalised her struggle in discussing the problems that she considered as reasons for her failure to reduce her weight since the HCP had reacted negatively to her sharing. Aside from HCPs' lack of understanding of the concept of patient empowerment, Skelton (1994) and Laverack (2009) argue that negative reactions by HCPs to patients' efforts to discuss their problems and to have some control over their treatment decision may be due to their hesitation to hand power to the patients. This was especially the case in this present study when the patients described their experiences of refusing to agree with or doubting the HCPs' recommendations, or when the patients insisted on their preferred choice. Hamann and colleagues (2011) reported similar findings in their study among HCPs in Germany. Aside from the lack of trust discussed earlier in 6.4.1.2, the HCPs' hesitation to allow the patients to be actively involved was also commonly due to their perception of the primacy of their recommended option and their lack of confidence in the patients' knowledge and ability that would enable them to effectively discuss and make the decision. Consequently, it was often the case that patients perceived their verbalising of their concerns, preferences and values as not being given enough attention, which was described by the patients as not being heard, being treated like a child or not being valued. For some patients, this left them feeling disempowered or powerless during the encounter, which then resulted in them being passive in their subsequent clinical encounters.

Overall, the discussion in this section shows that even though the patients feel empowered, the translation of this into active involvement in decisions is heavily influenced by the support of HCPs, thus further illuminating the power imbalance within the patient–HCP relationship. All of these findings support the assertion of previous scholars of the need for HCPs to compromise with patients by sharing their

decision-making power so that patients' sense of empowerment and their involvement in decisions can be supported (Kuokkanen & Leino-Kilpi, 2000; Hamann et al., 2011; Fredericks et al., 2012). Nonetheless, there is a lack of detail within the existing shared decision-making models in terms of addressing these situations where there are decision conflicts or power imbalances, including for times when the patient disagrees with the HCP's recommendation (Dewey, 2013).

6.6.3 Power, empowerment, habitus and capitals

Extensive discussion has already been presented on how patients and HCPs understand and practise shared decision-making and on how the shifting nature of the power to decide is heavily influenced by their respective beliefs, values and past experiences. This relationship resonates with Bourdieu's concept of habitus and its influence on individual practice (Bourdieu, 1977). Overall, habitus, as discussed in this study, depicts the essence of being and the whole gestalt of patients and HCPs. Their habitus is practically and socially constituted before proceeding to continuously shape their perceptions and actions. In addition, in accordance with Bourdieu's (1990) description of habitus, the past experiences of both patients and HCPs become embodied. Through these experiences, they learn the rules pertaining to the patient–HCP interaction and develop their 'feel for the game' of the healthcare field. This further supports Bourdieu's explanation of the link between individual practices and the field in which the practice has taken place.

Aside from habitus and field, the factors found to be related to patient involvement in decision-making in the context of this current study are in accordance with the concept of capital as it is described by Bourdieu (1986). The different capitals specified by Bourdieu were identified in this study as shaping the power relation between the patients and HCPs during decision-making as a social activity. The influences of all three concepts were found to not only strengthen each other but in certain circumstances to also be in competition with each other. In addition, in accordance with Bourdieu's assertion in his book *Distinction* (1984), where he emphasises the vital role played by culture in structuring the healthcare field,

Malaysian culture, which is deeply rooted among the people, can also be added to the complex background of factors determining the practice of patient involvement in this study context. Thus, as explained in Chapter 3, Bourdieu's work on the practice of an individual is found to be helpful in explaining the power relations between patients and HCPs that exist in this study.

Economic capital, which Bourdieu (1986) describes as the basis of the other capitals, is found to be associated with patients' perception of their right to be involved in decisions. They were accepting of the fact that it may not be possible for their management to be tailored to their preferences, needs and values since they attend publicly funded healthcare facilities and pay only a minimal rate. The limited time that can be spent with each patient and the options that can be offered to them by the HCPs in these facilities act as barriers to further involving patients in decisions and serve to accentuate the disadvantages of the patients in this study context, the majority of whom are from the low and middle socio-economic groups. The time constraint and limited number of options that can be offered to patients also highlight how HCPs tend to have only limited capacity for sharing the power to choose the best option.

Furthermore, the discussion on the findings related to HCPs' professionalism and its link to their expected roles and power was identified as according with Schinkel and Noordegraaf's (2011) description of professionalism as a form of symbolic capital. The HCPs' practice of empowering patients or allowing them to be actively involved in decisions was found to be linked to the need for HCPs to relinquish their traditional role and power of making decisions, instructing and directing their patients in the healthcare field, which has become firmly engrained among healthcare professionals. Besides, this study highlights the importance of HCPs' trust in the patients' ability to be involved in making the decision, with this being listed by Putnam and colleagues (1993) as social capital that influences the power dynamic between different groups.

Among all of the capitals described by Bourdieu, the most noteworthy form in this present study was found to be the cultural capital of both patients and HCPs that shaped the practice and power dynamic in making T2DM decisions. As an example of how cultural capital influences patient involvement in decision-making, both the patients and HCPs admitted that patients whom the HCPs believed to be better educated were granted more in the way of opportunity to become involved. This included patients with a higher level of education or those who were able to converse in English, thus reflecting the commonly held view among Malaysians that people who are proficient in English tend to be more educated (S. C. Choy & Troudi, 2006). The concept of cultural capital in the healthcare field was then further extended as cultural health capital. Cultural health capital was introduced to fulfil Bourdieu's assertion that cultural capital is heavily dependent on the 'field' (Shim, 2010). The field in this study refers mainly to the healthcare field as the social space where decisions on patients' T2DM management are made. Cultural health capital is defined as *"... the particular repertoire of cultural skills, verbal and non-verbal competencies, and interactional styles that can influence health care interactions at a given historical moment"* (Shim, 2010: p. 2). Drawing on the work of other scholars, Shim (2010) specified elements of Bourdieu's cultural capital as conforming to the healthcare field, which can then serve as a linkage between habitus and the social structure in the healthcare field. This will contribute to the placement of the person in the healthcare social hierarchy, similar to cultural capital.

Among the listed elements of cultural health capital are interactional styles (verbal and non-verbal competencies), a proactive attitude to the accumulation of knowledge, the ability to understand and use biomedical information, and an instrumental approach to disease management (Shim, 2010). The findings of this study indicate that HCPs, especially physicians, possess these elements more strongly than patients. Following Bourdieu's assertion, this results in a power imbalance between the patients and HCPs with regard to making a decision during the clinical encounter (Bourdieu & Wacquant, 1992). It is also often the case that the HCPs' recommendations and perspectives are considered to be both the best and the truth, since the HCPs are the ones in possession of greater power (Foucault, 1982).

A similar trend with regard to its effect can also be identified when exploring this matter among the patients. For example, patients who are able to understand their T2DM biomedical information tend to be more empowered and involved in making the decision if they are proactive in terms of effectively communicating with their HCPs to acquire as much information as possible about the options and decision, compared to patients who do not engage in any of these other elements despite being able to understand. Different degrees of cultural health capital possession among the patients gave rise to them being involved in decisions in different ways. However, comparable with the discussion about patients' sense of empowerment despite possessing cultural health capital, patient involvement remains dependent on their HCPs. A similar concern was raised by Dubbin and colleagues (2013), who found that the HCPs in their study held the power to decide upon the kinds of resources, behaviours and skills that mattered, in addition to their value, which was then used to determine how deeply the patients could be involved in the clinical encounter. Additionally, some of the HCPs who shared their power to decide with their patients recaptured that power if they believed that the patients could not be trusted or were not capable of adhering to a decision that they had made together. This was usually done more explicitly in comparison to the aforementioned patients' implicit way of reclaiming the power to determine their own care via non-adherence, as seen in 6.4.1.1.

The act of domination, which includes paternalism in the healthcare system, is considered to be a manifestation of power and often leads to inferior agents or groups being involved in acts of submission. However, it will only occur if such agents or groups appreciate the durable effects of their act of submission (Bourdieu, 1998). In this study, this can be identified as the belief by patients and HCPs that if the patients always listen to and carry out the instructions of their HCPs, this will ensure they have good access to the healthcare system, are perceived as good patients or have better control of their glycaemic level since a decision that is made by an HCP is regarded as being the best. Thus, this study may benefit from Shim's suggestion of focusing on the elements of cultural health capital as leverage to improve the effective engagement of patients with their HCPs during decision-making, aside from

improving HCPs' understanding of the concept of shared decision-making and patient-centred care.

Moreover, running in parallel to Bourdieu's claim of culture as being a form of capital, the influences of Malaysia's culture of high context, hierarchy, high power distance and saving face are evident in the level of patient involvement in decisions throughout this study. These cultural characteristics can also be identified as counteracting the patients' cultural health capital as they reinforce the boundaries between patients and HCPs in the healthcare social hierarchy that further strengthens the decisional power of the HCPs, especially that of the physicians, in this study context. Additionally, Islamic, Buddhist and Hindu teachings, which Frith (2000) states as being among the elements that make up the Malaysian habitus as a majority of Malaysians maintain a strong adherence to their faith, emphasise authority as being directed from the top of the hierarchical structure and that it should be respected, despite such teachings encouraging equality. All of these matters further complicate the effort to encourage shared decision-making in the study context.

However, as mentioned earlier, both the healthcare system and Malaysian society are changing. Consequently, what worked 10 to 20 years ago is no longer applicable and accepted without question today. This was clearly visible in the findings of this study, where the patients began to question things, either overtly or covertly, and were starting to become non-adherent or non-compliant with any treatment that they did not consider as fitting with their needs, preferences and values. Bourdieu referred to this as an indication of their cognitive struggle in adapting to the current needs and context (Bourdieu, 1998). This is where the shared decision-making model can be useful in terms of balancing the power between patients and HCPs in deciding their T2DM management.

6.6.4 HCPs' decisional power

In discussing HCPs' power to decide, among all of the HCPs, it was the physicians that were cited as the main decision makers in all of the interviews. Although other

HCPs are also actively involved in managing patients with T2DM in this present study context and have also been described as playing a significant role in the development of shared decision-making (Holmes-Rovner et al., 2000), the discussions that they had with the patients in this study mainly revolved around the decisions made by the physicians. Besides, most of the decisions that were made in the encounters between other HCPs and the patients were more intangible in nature, such as target setting, types of advice or information that the patients needed or decisions about patients' self-management. Although the patients in this present study were more comfortable sharing with other HCPs, the decision-making power of such other HCPs was perceived to be limited compared to that of the physicians as they did not have the authority to prescribe medication and undertake biomedical testing or referrals to other HCPs, which are commonly viewed as being more meaningful and complex. This raises the issue of their struggle to share the power and responsibility to decide with the patients, as they are also perceived by both themselves and others to have limited power to decide for the patients.

In bridging this perceived power gap between physicians and other HCPs, McKay and Narasimhan (2012) suggested that these HCPs attend inter-professional education so that their perceptions of each other and their own contribution in empowering the patients to be involved in decision-making can be improved. Nonetheless, a focused review of this power struggle by Paradis and Whitehead (2015) identified only a limited addressing of this matter in the existing literature on inter-professional education.

6.7 Contribution to the existing shared decision-making approach and its implementation

It can be concluded that decision-making for T2DM management in the study context is dominated by the biomedical model, patients' sick role and paternalism, thus posing a great challenge in the context of decisions being truly shared. Nonetheless, an awareness of the importance of having care that is centred around

patients' needs, preferences and values was found to motivate both the patients and HCPs to adopt the encouraging behaviours of shared decision-making, particularly in this study context that involves patients with T2DM as a chronic illness in an outpatient setting.

Based on the findings, shared decision-making may improve the experience of both patients and HCPs in making T2DM management decisions, with several emphases. Aside from proposing better information sharing and communication between HCPs and patients, and better acknowledgement of patients' experiential knowledge, which is commonly included in the existing shared decision-making models, this study also brings forward the potential benefit of a number of other elements that are found to be rarely discussed. These include (1) the active involvement of patients in setting the agenda of their clinical encounters and overall T2DM management; (2) the delaying of an HCP's recommendation; (3) allowing patients to evaluate the available options on a trial-and-error basis; and (4) actively involving patients in programmes, interventions or training related to shared decision-making.

This study further contributes to the existing shared decision-making model by supporting the importance of a good patient–HCP interpersonal relationship in T2DM management, as previously proposed by Entwistle and Watt (2006) together with Montori and colleagues (2006). Additionally, this study highlights that the therapeutic relationship is fundamental due to the potential advantage it offers in terms of enabling bi-directional trust and honest, two-way interaction among HCPs and their T2DM patients, so that the decision can be shared more effectively.

The application of Bourdieu's work in further investigating the emerging surrounding issues has highlighted the power issues together with the underlying Malaysian culture and social background that are present within the study context. These issues are found to further reinforce the existing gap between patients and HCPs that generally places patients in a disadvantaged position in the healthcare field. The power dynamic between patients and HCPs in decision-making is found to

not only be bound within the clinical encounter but to also extend outside the healthcare setting, where patients undertake their management in the absence of their HCPs. It has also emphasised the power struggle of the HCPs in the current study. Patients and HCPs battle to strike a balance between fulfilling the social and cultural expectation placed on them and the intention for patients to receive the care that is best suited to them. Therefore, this study makes a significant contribution to the conceptual development of shared decision-making by highlighting the need for it to be addressed, thus reflecting the lack of discussion on the patient–HCP power dynamic in the existing literature. The issue of power requires an explicit and distinct approach so that the highlighted issues can be successfully addressed within the shared decision-making framework. This is an addition to the detailed description of deliberation methods in order to guide HCPs in facing their dilemma and conflict regarding the making of decisions with their patients. In conclusion, this study supports a broader, more detailed and patient-centred conceptualisation of the shared decision-making framework that is relevant in terms of facilitating its effectiveness in the management of T2DM patients in a Malaysian outpatient setting.

CHAPTER 7: CONCLUSION

7.1 Introduction

The research aim of this study was established based on the issues highlighted in the first two chapters. Chapters 1 and 2 identified the need to understand the involvement of T2DM patients in decision-making in Malaysia. As such, this empirical study has explored the subjective accounts of different groups of stakeholders who are directly involved in the management of patients with T2DM. These stakeholders were interviewed with the aim of gaining a comprehensive understanding of patient involvement in decision-making practice and its related factors, the key findings of which are summarised in this final chapter. The implications and recommendations for healthcare policy, practice and education are presented next. This is done to answer the research question of this study on how shared decision-making can be operationalised as an approach to facilitating patient involvement in decision-making in this study context. Finally, recommendations for future research are outlined.

7.2 Summary of the research findings

Overall, several key findings have emerged from this study. The findings in Chapter 4 highlight the gap between the participants' conceptualisation of patient involvement in decision-making and shared decision-making as the ideal approach, which is also found to further shape the variety of patient involvement in decision-making practice. Shared decision-making is described by HCPs as the securing of patients' agreement and compliance with their recommendation, which is mainly achieved through HCPs' technical knowledge and medical expertise. Consequently, the information provided by the HCPs was found to be geared towards the achievement of this aim compared to the main aim of shared decision-making, that of putting patients' needs, preferences, beliefs and values at the centre, together with HCPs' medical expertise, when making the decision (de Silva, 2012). However, the patients' descriptions of shared decision-making were more aligned to the approach as they illustrated their expectation of it as a way of ensuring that the concerns and

information they share concerning their day-to-day T2DM management can be properly addressed and taken into consideration when a decision is made. These findings further highlight the discordance between patients and HCPs in terms of the focus in clinical encounters.

Besides highlighting the recurrent issues related to the lack of shared decision-making practice, including the lack of information provision by HCPs, notably in relation to the other available options and side effects, and the lack of any deliberation of the options against patients' needs, preferences and values, the findings of this study bring forward the issue of patients' lack of information sharing and the disassociation of patients' agreement and adherence that is barely touched upon in the current literature. As such, it can be concluded that the decisions on the management of T2DM in the study context are not truly shared, thereby resulting in patients' non-adherence and dissatisfaction.

Further exploration revealed the lack of patient involvement in the current decision-making process to be linked to the lack of a good patient–HCP interpersonal relationship, a lack of communication skills on both sides, the participants' conforming to the social expectations of their own and each other's roles, and the issue of power that exists in the context of making health decisions. Bourdieu's work was utilised in the attempts in this study to make sense of the power issues involved in the practice of patient involvement in decision-making. Through its application, there appears to be a power dynamic within decision-making that currently leans towards the HCPs. This is because of the dominance of the biomedical model over the patient-centred model, in addition to the fact that the involvement of patients in decisions continues to be heavily dependent on the allowance and facilitation afforded by their HCPs. The embodied habitus and capitals among the patients and HCPs in this study place the HCPs higher in the social hierarchy of the healthcare field. Therefore, it can be said that the patients face challenges in terms of being involved in making the decision during the clinical encounter. Nonetheless, the findings also suggest that there is a power shift in relation to the making of the

decision as the management of T2DM in the outpatient setting is mostly performed by the patient outside of the healthcare facilities and entails a high degree of patient self-management. As such, the ultimate power to decide lies in the patients' hands.

Moreover, since different groups of HCPs were involved in this study, the power struggle could also be sensed among them; in other words, it occurs not only between themselves and their patients but also among them. The challenges faced by the HCPs pertaining to the issue of power include the dilemma they face in balancing their ethical foundation of beneficence and respecting patients' autonomy, their limited opportunity for involving patients due to the constraints on the resources available at their facilities, the language barrier and they themselves having limited power to decide.

In summary, this study contributes to the current body of knowledge in terms of understanding the involvement in decision-making among T2DM patients, who in Malaysia mostly attend appointments in an outpatient setting. This is in addition to its valuable contribution of using Bourdieu's social theory in exploring the matter and highlighting the Malaysian social and cultural dimensions (hierarchical structure, high power distance, high context culture and the culture of saving face) that further reinforce the factors and elements that serve to maintain the gap between the practice and ideal aspiration of shared decision-making. As a result, this study appears to support the implementation of a broader conceptualised shared decision-making approach.

7.3 Implications and recommendations

The findings of this study highlight the differences between ethical and theoretical ideals and the actual practice of involving the patient in their decisions. This section therefore addresses the final research question of this study on how shared decision-making can be operationalised in the management of T2DM in this study context. In this section, the implications of the findings in terms of Malaysian health policy,

practice and education are presented along with recommendations that can address the differences and facilitate the adoption of the shared decision-making model as one approach to patient-centred care in the Malaysian healthcare system.

7.3.1 Healthcare policy

The government healthcare policy and guidelines in Malaysia have been found to adopt a patient-centred care approach to managing patients in the context of the growing issue of patient autonomy and in the realisation of its benefits with regard to the health management of patients. However, its illustration is generally based on patients' involvement in their care and is lacking in terms of patient involvement in the decisions about the care itself, with this often being limited to informed consent. This is supported by the findings of this study whereby the HCPs' descriptions of patient involvement in decision-making were found to accord more with the obtaining of patients' consent to their recommended treatment choice. However, as previously discussed in the Findings and Discussion chapters, patient involvement in decisions relating to T2DM as a chronic illness may require more than this. The findings of this study appear to highlight the need for a broader conceptualisation of the shared decision-making approach in terms of facilitating its effectiveness in the study context. This includes the following three elements: the potential benefit of continuity of care among T2DM in fostering the patient–HCP therapeutic relationship; the integration of problem identification into shared decision-making; and the integration of shared decision-making with other patient-centred approaches, including motivational interviewing and self-management support.

Also evident in this study is the potentially large contribution to be made by non-physician HCPs, including nurses, in facilitating shared decision-making. Thus, it seems relevant to suggest that access to this group of HCPs is improved, in addition to a better acknowledgement of their roles in managing T2DM patients. This is in addition to the need for a policy analysis to explore HCPs' practice of handling health resources and empowering patients. Finally, this study highlights the need for better recognition of patients' ability to contribute to the healthcare system, which

can be achieved through the support lent by government policies and documents on the equality of patients' and HCPs' respective contributions in the healthcare system.

7.3.2 Healthcare practice

The findings have clearly illustrated that there continues to be a lack of patient involvement in decision-making in the study context and that paternalistic approaches are used when making most of the decisions. The first measure that can be taken to enable and encourage patient involvement in decision-making is to introduce and integrate a programme based on this model into the management of T2DM in the study context. Shared decision-making may facilitate the involvement of patients from the very beginning and throughout the decision-making process, which would subsequently facilitate their further involvement and management. However, the model should be adopted carefully and may require a degree of alteration in order for it to fit the needs of the study context.

Since the findings of the study point to the significant dominance of the role and power imbalance of HCPs during the clinical encounter, an awareness of the importance of their partnership and equipoise of power with patients when making decisions should be instilled among HCPs. This becomes more significant in this study context where there is a much more robust hierarchical culture than is found in Western culture, and where the equipoise of power between patients and HCPs in making decisions is missing from the norms, beliefs and values (Geertz, 1973a; Thomas et al., 2011). Understanding among HCPs of the importance of patient involvement in their own care also needs to be extended to cover the decision-making process. The HCPs in this study may also benefit from undertaking courses and training in shared decision-making in order to develop a better understanding of the approach and its related skills and to then incorporate these into their practice. Such training may lead to a change in HCPs' perception of patient involvement in decision-making, from one based merely on providing information and obtaining patients' agreement to a two-way interaction that involves unbiased deliberation with their patients of the decision that needs to be made.

In this present study, HCPs' communication skills were found to greatly influence patient involvement in decision-making. Based on the findings, training in communication skills that is able to encourage transparent two-way interaction when deciding upon patients' care should focus on the following four important skills among HCPs: (1) the skill of sharing unbiased and adequate information; (2) the skill of eliciting patients' concerns, preferences, beliefs and values; (3) the skill of negotiating, and (4) the skill of attentive listening and empathetic responding. According to a study by Bylund and colleagues (2010), communication skills training for HCPs that covers these aspects can increase the potential for agendas and goals to be articulated, for patients' understanding to be confirmed and for patients to ask questions. Based on this study, good communication skills can also facilitate a good interpersonal relationship, which in turn improves patients' honest sharing and trust in HCPs.

Further communication training tailored to the study context is also needed since nonverbal cues from both patients and HCPs have been shown to play a major role during their interaction when making the decision. Reflecting Malaysia's high-context culture, the patients in this study appeared to be highly sensitive to their HCPs' body language, facial expressions and tone of voice during their encounters with them. The HCPs, on the other hand, seemed to be insensitive to their patients' verbal cues and to the possibility of there being different meanings behind the patients' verbalised responses or information. If HCPs master good communication skills and are able to better tailor their responses to the needs of their patients, then the patients may feel more comfortable disclosing important information and actively contribute to the deliberation on their T2DM decisions.

Despite the lack of patient involvement in existing shared decision-making interventions as identified in a review by Coulter and colleagues (2015), patient involvement in such an intervention in this study context may facilitate its effectiveness. From the findings of this study, an awareness campaign among patients seems to be relevant for inclusion in the shared decision-making programme

as it may increase the value that patients place on their everyday experience of dealing with T2DM, which may then motivate them to become actively involved. The involvement of patients in any shared decision-making programme may also further educate those who are not interested in playing an active role and who prefer for the HCPs to decide for them. Nonetheless, the effort to educate them is suggested in this study not with the intention of disrespecting their preferred role or to force them to participate but rather to make them aware of the benefit of their involvement in terms of helping them to carry out their T2DM management in a way that takes into account the input that they share.

The discussion of the findings also highlights the need for patients' cultural health capital to be strengthened so that the gap between patients and HCPs can be narrowed and to further ease patient involvement in the decision. In this study, the patients were perceived to be lacking in health literacy, which then limits their involvement in decision-making. Thus, shared decision-making in this study context may benefit from an improvement in the health literacy of patients. As a measure, this could help patients to acquire further understanding of the medical information related to their T2DM and to improve their ability to identify the problems that need to be shared with their HCPs. This in turn may further ease their involvement and enable them to gain the attention of their HCPs. When taken in isolation, however, measures to improve patients' health literacy and their ability to identify problems appeared to be insufficient in relation to promoting their involvement. Patients also need to be equipped with good skills in critical thinking and communicating their problems, preferences, values and beliefs, both effectively and in a medically intelligible manner. Shepherd and colleagues (2011) suggested using lists of questions that patients can ask their HCPs as a way of promoting their active involvement in decisions.

7.3.3 Education

It is evident from the findings of this study that the way decisions were made focused mainly on the patients' clinical status and outcomes and did not give sufficient consideration to their concerns, needs and preferences, owing to a reliance on the

biomedical model. Hence, a revision of the HCPs' curriculum to further emphasise patient-centred care, especially shared decision-making, would seem to be beneficial in this study context. This will facilitate the HCPs' embodiment of this approach over the traditional biomedical approach, which is no longer suited to the current healthcare landscape. The incorporation of patient-centred care from the beginning of the HCPs' education and career has the potential to promote the required changes within the healthcare system so that patients' autonomy can be respected and a more holistic type of consideration can be given to their overall well-being.

In addition, since the management of T2DM in the study context involved different groups of HCPs, the effort to improve patient involvement in decision-making may benefit from the integration of shared decision-making into the existing inter-professional education, as suggested by Col and colleagues (2011). In addition to understanding the concept of shared decision-making and acquiring relevant skills, which were previously mentioned in 7.3.1, they proposed that inter-professional education on shared decision-making should include an understanding of inter-professional sensitivities and the roles played by different professions in the management of T2DM.

7.4 Recommendations for future research

The findings of this study contribute to the understanding of the experiences and views of both T2DM patients and the HCPs who are responsible for managing this health problem. Nonetheless, as discussed in the limitations section of Chapter 3, the language barrier between the researcher and participants may have served to limit the level of exploration among those patients who were unable to converse in either English or Malay. Having a translator could have helped with both the recruitment of patients who were unable to converse in either of these languages and in assisting those Chinese and Indian participants with neither Malay nor English as their native language to more freely describe their experiences and views in their mother tongue. This may have generated a richer description and understanding from the multiple

Malaysian cultural backgrounds that could not be achieved in this study due to the limited numbers of Chinese and Indian participants.

On the other hand, as the findings of this study cannot be generalised to a larger population due to its qualitative nature, the scope remains for future quantitative research to further expand these findings as part of a more extensive yet context-specific study. Further exploration can also be carried out to identify the strategies that patients and HCPs perceive would be needed to further involve patients in their decisions.

This study also highlights a number of essential matters concerning shared decision-making that have not previously been the subject of extensive discussion in the existing literature. These include the identification of patients' problems that need to be addressed during their encounter and their need for a decision to be made, the information sharing by patients during the decision-making and the HCPs' trust in their patients to be involved in making the decisions. Further exploration of these issues may contribute to the establishment of a more comprehensive understanding of patient involvement in the decision. Furthermore, the role expectation of both patients and HCPs as one of the reasons for the power imbalance between both groups, with the latter having been identified as the main barrier to patient involvement in decisions, could be explored further. The extent of the exploration and discussion of this important barrier was limited in this study since it was identified after the data collection had ended.

Finally, with a passion for encouraging Malaysian T2DM patients to be actively involved with and responsible for their health and related decisions, the findings of this study could be integrated with those of potential future studies to achieve the ultimate aim of developing a shared decision-making programme capable of facilitating the active involvement of T2DM patients in Malaysia.

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Appendices

Appendix I: Participants information sheet for the patients

English version

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INFORMATION SHEET (PATIENT)

Title: Shared Decision-Making in the Management of Type 2 Diabetes Mellitus in Malaysia: The Perspectives of Patients and Healthcare Professionals (HCPs)

You are being invited to participate in a research study. However, before you decide whether to accept this invitation it is important that you know what this study is about, why it is being undertaken and what it will involve. Please take the time to read this information and feel free to discuss this with other people. Please do not hesitate to contact one of the researchers if there is anything that is not clear or if you would like more information. Our contact details are given at the end of this sheet. Please take time to decide whether or not you would like to take part in this study.

Study title:
Shared Decision-Making in the Management of Type 2 Diabetes Mellitus in Malaysia: The Perspectives of Patients and HCPs

What is this study about?
This study is to explore the perspectives of the type 2 diabetic patients and their HCPs regarding patient involvement in decision-making and also shared decision-making.

Why is this study being carried out?
Patient involvement in their healthcare management has been widely encouraged around the world. Shared decision-making is an approach in decision-making in which the patients and their HCPs collaboratively make the best treatment choice. This study will provide information on the perspectives of patients and HCPs regarding this approach in the management of type 2 diabetes mellitus to facilitate its adoption in the Malaysian healthcare system.

Do I have to take part?
It is entirely up to you whether you take part in this study and your participation is voluntary.

What would I have to do?

If you decide to take part it would involve taking part in an individual interview with one researcher (Ashikin Atan, Principle Investigator). The interview will last approximately 60 minutes and will take place at a time and location convenient for participants. It is important that you answer all of the questions asked by the researcher honestly and completely. With your permission, we would like to record the interview for later data analysis. The recording will be used for research purposes only, anonymised and will be stored securely until it is destroyed approximately after 10 years.

Confidentiality

Everything you or any other participants will say will be kept **confidential** between you and the researcher. Your name will not be attached to any documents nor will you be identified as a participant in this study or in any subsequent publications of study results.

What will the study result be used for?

The study will contribute to an understanding of how the participants perceived shared decision-making in the management of type 2 diabetes mellitus in Malaysia. With the result obtained, it is hoped that this study will be able to suggest ways of facilitating the adoption of this concept in the Malaysian healthcare system.

Who is funding the study?

The study is funded by the Ministry of Education, Malaysia.

Are there possible benefits or risks in taking part?

In taking part you ensure that your voice is heard on the issue but apart from that there are no benefits or risks in taking part.

Can I change my mind?

Should you change our mind and no longer wish to take part in the study just let us know. You do not need to give us any reason for this change. Withdrawal from this study will not affect the treatment you receive for your condition.

How can I contact the researchers to take part in this study or to get further information?

Please contact us if you want to take part in the study or have any further questions:

- Ashikin Atan at ashikinatan08@gmail.com or phone +6013-7411395 (Malaysia)
- Dr Sarah Rhynas at Sarah.Rhynas@ed.ac.uk or phone +44 (0)131 650 3882 (United Kingdom)
- Professor Tonks Fawcett at t.fawcett@ed.ac.uk or phone +44(0)1316503883 (United Kingdom)

All at: School of Health in Social Science
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And finally…. Thank you for taking the time reading this information leaflet! We hope to see you soon!

Malay version

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RISALAH MAKLUMAT PESERTA (PESAKIT)

Tajuk: Membuat Keputusan Bersama dalam Pengurusan Diabetes Mellitus Jenis 2 di Malaysia: Perspektif Pesakit dan Profesional Kesihatan

Anda dijemput untuk mengambil bahagian dalam penyelidikan ini. Namun, sebelum anda membuat keputusan untuk menerima jemputan ini, anda perlu ketahui serba sedikit mengenai penyelidikan ini. Sila baca maklumat berikut dengan teliti dan sebarang perbincangan adalah digalakkan. Sekiranya terdapat keraguan terhadap maklumat yang diberi atau memerlukan maklumat tambahan, anda boleh menghubungi mana-mana penyelidik yang terlibat. Nombor telefon dan alamat email penyelidik-penyelidik yang terlibat adalah seperti yang tertera di penghujung risalah maklumat peserta ini.

Tajuk penyelidikan:
Membuat Keputusan Bersama dalam Pengurusan Diabetes Mellitus Jenis 2 di Malaysia: Perspektif Pesakit dan Profesional Kesihatan

Apakah tujuan penyelidikan ini dijalankan?
Penyelidikan ini bertujuan untuk meneroka perspektif pesakit diabetes mellitus jenis 2 dan ahli profesional kesihatan mengenai penyertaan pesakit dalam proses membuat keputusan dan juga membuat keputusan bersama.

Mengapa penyelidikan ini dijalankan?
Penglibatan pesakit di dalam pengurusan penjagaan kesihatan adalah digalakkan di serata dunia. Membuat keputusan bersama adalah salah satu pendekatan dalam proses membuat keputusan dimana pesakit dan ahli profesional kesihatan bekerjasama dalam memilih rawatan yang terbaik. Penyelidikan ini akan memberikan maklumat mengenai perspektif pesakit dan ahli profesional kesihatan berkenaan pendekatan ini dalam pengurusan diabetes mellitus jenis 2 agar ia boleh diintegrasikan ke dalam sistem penjagaan kesihatan Malaysia

Adakah saya perlu menyertai penyelidikan ini?
Penyertaan anda adalah bergantung sepenuhnya kepada persetujuan anda dan secara sukarela.

Apa yang perlu saya lakukan?
Sekiranya anda bersetuju untuk menyertai penyelidikan ini, satu sesi temubual akan dilakukan bersama salah seorang penyelidik (Ashikin Atan, Penyelidik Utama). Sesi tersebut akan berlangsung selama lebih kurang 60 minit, pada masa dan di lokasi mengikut kemudahan anda. Adalah amat penting untuk ada menjawab kesemua soalan yang ditanyakan oleh penyelidik dengan jujur dan lengkap. Dengan izin anda, sesi temubual tersebut akan direkodkan untuk dianalisa. Rekod temubual hanya akan digunakan untuk tujuan penyelidikan sahaja, maklumat peribadi anda akan dirahsiakan dan segala rekod akan dilupuskan selepas 10 tahun.

Kerahsiaan
Segala maklumat yang anda dan peserta lain berikan akan dirahsiakan antara anda dan penyelidik. Nama anda tidak akan disertakan dalam mana-mana dokumen dan mana-mana penerbitan keputusan penyelidikan.

Apakah kegunaan keputusan penyelidikan?
Penyelidikan ini akan menyumbang kepada kefahaman terhadap perspektif pesakit dan ahli profesional kesihatan mengenai membuat keputusan bersama dalam pengurusan diabetes mellitus jenis 2 di Malaysia. Daripada keputusan penyelidikan, cadangan mengenai langkah-langkah agar konsep ini boleh digunapakai di dalam system penjagaan kesihatan di Malaysia akan diberi.

Nama penaja
Penyelidikan ini ditaja oleh Kementerian Pendidikan, Malaysia.

Apakah manfaat atau risiko penglibatan di dalam penyelidikan?
Penyertaan anda akan membolehkan pandangan dan suara anda mengenai isu yang diselidik didengari. Selain daripada itu, tiada sebarang manfaat ataupun risiko dalam menyertai penyelidikan ini.

Bolehkah saya bertukar fikiran?
Sekiranya anda bertukar fikiran dan tidak lagi mahu menyertai penyelidikan ini, anda hanya perlu maklumkan kepada kami. Anda tidak perlu memberi sebarang sebab. Penarikan diri daripada penyelidikan ini tidak akan menpengaruhi rawatan yang anda terima.

Bagaimana saya boleh menghubungi penyelidik-penyelidik yang terlibat dalam penyelidikan ini ataupun untuk mendapatkan maklumat lanjut?
Sila hubungi kami sekiranya anda bersetuju untuk mengambil bahagian dalam penyelidikan ini ataupun mempunyai sebarang soalan berkenaan penyelidikan ini, anda boleh menghubungi:

- Ashikin Atan di ashikinatan08@gmail.com atau telefon +6013-7411395 (Malaysia)
- Dr Sarah Rhynas di Sarah.Rhynas@ed.ac.uk atau telefon +44 (0)131 650 3882 (United Kingdom)
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The University of Edinburgh
Medical School, Doorway 6
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Dan akhir sekali…..

Terima kasih kerana meluangkan masa membaca risalah maklumat ini. Kami berharap akan bertemu anda lagi!

Appendix 2: Participants information sheet for the HCPs

English version

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Email: ashikinatan08@gmail.com

INFORMATION SHEET (HEALTHCARE PROFESSIONAL)

Title: Shared Decision-Making in the Management of Type 2 Diabetes Mellitus in Malaysia: The Perspectives of Patients and Healthcare Professionals (HCPs)

You are being invited to participate in a research study. However, before you decide whether to accept this invitation it is important that you know what this study is about, why it is being undertaken and what it will involve. Please take the time to read this information and feel free to discuss this with other people. Please do not hesitate to contact one of the researchers if there is anything that is not clear or if you would like more information. Our contact details are given at the end of this sheet. Please take time to decide whether or not you would like to take part in this study.

Study title:
Shared Decision-Making in the Management of Type 2 Diabetes Mellitus in Malaysia: The Perspectives of Patients and HCPs.

What is this study about?
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Do I have to take part?
It is entirely up to you whether you take part in this study and your participation is voluntary.
What would I have to do?

If you decide to take part it would involve taking part in an individual interview with one researcher (Ashikin Atan, Principle Investigator). The interview will last approximately 60 minutes and will take place at a time and location convenient for participants. It is important that you answer all of the questions asked by the researcher honestly and completely. With your permission, we would like to record the interview for later data analysis. The recording will be used for research purposes only, anonymised and will be stored securely until it is destroyed approximately after 10 years.

Confidentiality

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What will the study result be used for?

The study will contribute to an understanding of how the participants perceived shared decision-making in the management of type 2 diabetes mellitus in Malaysia. With the result obtained, it is hoped that this study will be able to suggest ways of facilitating the adoption of this concept in the Malaysian healthcare system.

Who is funding the study?

The study is funded by the Ministry of Higher Education, Malaysia.

Are there possible benefits or risks in taking part?

In taking part you ensure that your voice is heard on the issue but apart from that there are no benefits or risks in taking part.

Can I change my mind?

Should you change our mind and no longer wish to take part in the study just let us know. You do not need to give us any reason for this change.

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And finally….

Thank you for taking the time reading this information leaflet! We hope to see you soon!

Malay version

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RISALAH MAKLUMAT PESERTA (PROFESIONAL KESIHATAN)

Tajuk: Membuat Keputusan Bersama dalam Pengurusan Diabetes Mellitus Jenis 2 di Malaysia: Perspektif Pesakit dan Profesional Kesihatan

Anda dijemput untuk mengambil bahagian dalam penyelidikan ini. Namun, sebelum anda membuat keputusan untuk menerima jemputan ini, anda perlu ketahui serba sedikit mengenai penyelidikan ini. Sila baca maklumat berikut dengan teliti dan sebarang perbincangan adalah digalakkan. Sekiranya terdapat keraguan terhadap maklumat yang diberi atau memerlukan maklumat tambahan, anda boleh menghubungi mana-mana penyelidik yang terlibat. Nombor telefon dan alamat email penyelidik-penyelidik yang terlibat adalah seperti yang tertera di penghujung risalah maklumat peserta ini.

Tajuk penyelidikan:
Membuat Keputusan Bersama dalam Pengurusan Diabetes Mellitus Jenis 2 di Malaysia: Perspektif Pesakit dan Profesional Kesihatan

Apakah tujuan penyelidikan ini dijalankan?
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Mengapa penyelidikan ini dijalankan?
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Adakah saya perlu menyertai penyelidikan ini?
Penyertaan anda adalah bergantung sepenuhnya kepada persetujuan anda dan secara sukarela.

Apa yang perlu saya lakukan?
Sekiranya anda bersetuju untuk menyertai penyelidikan ini, satu sesi temubual akan dilakukan bersama salah seorang penyelidik (Ashikin Atan, Penyelidik Utama). Sesi tersebut

akan berlangsung selama lebih kurang 60 minit, pada masa dan di lokasi mengikut kemudahan anda. Adalah amat penting untuk ada menjawab kesemua soalan yang ditanyakan oleh penyelidik dengan jujur dan lengkap. Dengan izin anda, sesi temubual tersebut akan direkodkan untuk dianalisa. Rekod temubual hanya akan digunakan untuk tujuan penyelidikan sahaja, maklumat peribadi anda akan dirahsiakan dan segala rekod akan dilupuskan selepas 10 tahun.

Kerahsiaan

Segala maklumat yang anda dan peserta lain berikan akan dirahsiakan antara anda dan penyelidik. Nama anda tidak akan disertakan dalam mana-mana dokumen dan mana-mana penerbitan keputusan penyelidikan.

Apakah kegunaan keputusan penyelidikan?

Penyelidikan ini akan menyumbang kepada kefahaman terhadap perspektif pesakit dan ahli profesional kesihatan mengenai membuat keputusan bersama dalam pengurusan diabetes mellitus jenis 2 di Malaysia. Daripada keputusan penyelidikan, cadangan mengenai langkah-langkah agar konsep ini boleh digunapakai di dalam system penjagaan kesihatan di Malaysia akan diberi.

Nama penaja

Penyelidikan ini ditaja oleh Kementerian Pendidikan, Malaysia.

Apakah manfaat atau risiko penglibatan di dalam penyelidikan?

Penyertaan anda akan membolehkan pandangan dan suara anda mengenai isu yang diselidik didengari. Selain daripada itu, tiada sebarang manfaat ataupun risiko dalam menyertai penyelidikan ini.

Bolehkah saya bertukar fikiran?

Sekiranya anda bertukar fikiran dan tidak lagi mahu menyertai pemyelidikan ini, anda hanya perlu maklumkan kepada kami. Anda tidak perlu memberi sebarang sebab.

Bagaimana saya boleh menghubungi penyelidik-penyelidik yang terlibat dalam penyelidikan ini ataupun untuk mendapatkan maklumat lanjut?

Sila hubungi kami sekiranya anda bersetuju untuk mengambil bahagian dalam penyelidikan ini ataupun mempunyai sebarang soalan berkenaan penyelidikan ini, anda boleh menghubungi:

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Edinburgh EH8 9AG, United Kingdom

Dan akhir sekali…..

Terima kasih kerana meluangkan masa membaca risalah maklumat ini. Kami berharap akan bertemu anda lagi!

Appendix 3: Informed consent form (Patient)

English version

ASHIKIN ATAN
THE UNIVERSITY OF EDINBURGH
SCHOOL OF HEALTH IN SOCIAL SCIENCE
DOOR WAY 6
MEDICAL QUAD
TEVIOT PLACE
EDINBURGH EH8 9AG
Telephone: +6013-7411395
Email: ashikinatan08@gmail.com

INFORMED CONSENT FORM (PATIENT)

Title of Study: Shared Decision-Making in the Management of Type 2 Diabetes Mellitus in Malaysia: The Perspectives of Patients and Healthcare Professionals (HCPs)

By signing below, I confirm the following: **Please initial each boxes**

- I have been given oral and written information for the above study and have read and understood the information given. ☐

- I have had sufficient time to consider participation in the study and have had the opportunity to ask questions and all my questions have been answered satisfactorily. ☐

- I understand that my participation is voluntary and I can at anytime free withdraw from the study without giving a reason and this will in no way affect my future treatment. ☐

- I understand the risks and benefits, and I freely give my informed consent to participate under the conditions stated. I understand that I must follow the researcher's instructions related to my participation in the study. ☐

- I understand that study staff, qualified reviewers and auditors, the sponsor or its affiliates, and governmental or regulatory authorities, have direct access to my medical record in order to make sure that the study is conducted correctly and the data are recorded correctly. All personal details will be treated as **STRICTLY CONFIDENTIAL**. ☐

☐

- I understand that anonymised extracts of interviews may be used in any reports, publications or presentations emerging from this project.

- I will receive a copy of this subject information/informed consent form signed and dated to bring home. ☐

- I agree to take part in this study. ☐

Participant:

Signature: I/C number:

Name: Date:

Investigator conducting informed consent:

Signature: I/C number:

Name: Date:

Malay version

ASHIKIN ATAN
THE UNIVERSITY OF EDINBURGH
SCHOOL OF HEALTH IN SOCIAL SCIENCE
DOOR WAY 6
MEDICAL QUAD
TEVIOT PLACE
EDINBURGH EH8 9AG
No. Tel: +6013-7411395
Email: ashikinatan08@gmail.com

BORANG PERSETUJUAN PESERTA (PESAKIT)

Tajuk: Membuat Keputusan Bersama dalam Pengurusan Diabetes Mellitus Jenis 2 di Malaysia: Perspektif Pesakit dan Profesional Kesihatan

Dengan menandatangani di bawah, saya mengesahkan bahawa: Sila tandatangan ringkas di setiap kotak

- Saya telah diberi maklumat tentang penyelidikan di atas secara lisan dan bertulis dan saya telah membaca dan memahami segala maklumat yang diberikan dalam risalah ini. ☐

- Saya telah diberikan masa yang secukupnya untuk mempertimbangkan penyertaan saya dalam penyelidikan ini dan telah diberi peluang untuk bertanyakan soalan dan semua persoalan saya telah dijawab dengan sempurna dan memuaskan. ☐

- Saya juga faham bahawa penyertaan saya adalah secara sukarela dan pada bila-bila masa saya bebas menarik diri daripada penyelidikan ini tanpa harus memberi sebarang alasan dan ianya sama sekali tidak akan menjejaskan rawatan perubatan saya pada masa akan datang. ☐

- Saya juga memahami tentang risiko dan manfaat penyelidikan ini dan saya secara sukarela memberi persetujuan untuk menyertai penyelidikan ini di bawah syarat-syarat yang telah dinyatakan di atas. Saya faham saya harus mematuhi nasihat dan arahan yang berkaitan dengan penyertaan saya dalam penyelidikan ini daripada penyelidik. ☐

- Saya faham bahawa kakitangan penyelidikan, pemantau dan juruaudit

terlatih , pihak penaja atau gabungannya, dan pihak berkuasa kerajaan atau undang-undang, mempunyai akses langsung dan boleh menyemak laporan perubatan saya bagi memastikan penyelidikan ini dijalankan dengan betul dan data direkodkan dengan betul. Segala maklumat dan data peribadi akan dianggap sebagai **SULIT**. ☐

- Saya faham bahawa petikan tidak bernama daripada temubual mungkin akan digunakan di dalam mana-mana laporan, penerbitan, atau pembentangan hasil daripada projek ini. ☐

- Saya akan menerima satu salinan 'Risalah Maklumat Peserta dan Borang Persetujuan Peserta' yang telah lengkap dengan tarikh dan tandatangan untuk dibawa pulang ke rumah. ☐

- Saya bersetuju untuk mengambil bahagian dalam penyelidikan ini. ☐

Peserta:

Tandatangan: Nombor K/P:

Nama: Tarikh :

Penyelidik yang mengendalikan proses menandatangani borang keizinan:

Tandatangan: Nombor K/P:

Nama: Tarikh :

Appendix 4: Informed consent form (HCPs)

English version

ASHIKIN ATAN
THE UNIVERSITY OF EDINBURGH
SCHOOL OF HEALTH IN SOCIAL SCIENCE
DOOR WAY 6
MEDICAL QUAD
TEVIOT PLACE
EDINBURGH EH8 9AG
Telephone: +6013-7411395
Email: ashikinatan08@gmail.com

INFORMED CONSENT FORM (HEALTHCARE PROFESSIONAL)

Title of Study: Shared Decision-Making in the Management of Type 2 Diabetes Mellitus in Malaysia: The Perspectives of Patients and Healthcare Professionals (HCPs)

By signing below, I confirm the following: **Please initial each boxes**

- I have been given oral and written information for the above study and have read and understood the information given. ☐

- I have had sufficient time to consider participation in the study and have had the opportunity to ask questions and all my questions have been answered satisfactorily. ☐

- I understand the risks and benefits, and I freely give my informed consent to participate under the conditions stated. I understand that I must follow the researcher's instructions related to my participation in the study. ☐

- All personal details will be treated as **STRICTLY CONFIDENTIAL**. ☐

- I understand that the researchers, reviewers and trained auditor, the sponsor, and the government or law authorities have direct access to my medical record to ensure this study is ☐

- I understand that study staff, qualified reviewers and auditors, the sponsor or its affiliates, and governmental or regulatory authorities, have direct ☐

access to the data in order to make sure that the study is conducted correctly and the data are recorded correctly. All personal details will be treated as **STRICTLY CONFIDENTIAL**.

- I understand that anonymised extracts of interviews may be used in any reports, publications or presentations emerging from this project. ☐

- I will receive a copy of this subject information/informed consent form signed and dated to bring home. ☐

- I agree to take part in this study. ☐

Participant:

Signature: I/C number:

Name: Date:

Investigator conducting informed consent:

Signature: I/C number:

Name: Date:

Malay version

ASHIKIN ATAN
THE UNIVERSITY OF EDINBURGH
SCHOOL OF HEALTH IN SOCIAL SCIENCE
DOOR WAY 6
MEDICAL QUAD
TEVIOT PLACE
EDINBURGH EH8 9AG
No. Tel: +6013-7411395
Email: ashikinatan08@gmail.com

BORANG PERSETUJUAN PESERTA (PROFESIONAL KESIHATAN)

Tajuk: Membuat Keputusan Bersama dalam Pengurusan Diabetes Mellitus Jenis 2 di Malaysia: Perspektif Pesakit dan Profesional Kesihatan

Dengan menandatangani di bawah, saya mengesahkan bahawa: Sila tandatangan ringkas di setiap kotak

- Saya telah diberi maklumat tentang penyelidikan di atas secara lisan dan bertulis dan saya telah membaca dan memahami segala maklumat yang diberikan dalam risalah ini. ☐

- Saya telah diberikan masa yang secukupnya untuk mempertimbangkan penyertaan saya dalam penyelidikan ini dan telah diberi peluang untuk bertanyakan soalan dan semua persoalan saya telah dijawab dengan sempurna dan memuaskan. ☐

- Saya juga faham bahawa penyertaan saya adalah secara sukarela dan pada bila-bila masa saya bebas menarik diri daripada penyelidikan ini tanpa harus memberi sebarang alas an. ☐

- Saya juga memahami tentang risiko dan manfaat penyelidikan ini dan saya secara sukarela memberi persetujuan untuk menyertai penyelidikan ini di bawah syarat-syarat yang telah dinyatakan di atas. Saya faham saya harus mematuhi nasihat dan arahan yang berkaitan dengan penyertaan saya dalam penyelidikan ini daripada penyelidik. ☐

- Saya faham bahawa kakitangan penyelidikan, pemantau dan juruaudit terlatih , pihak penaja atau gabungannya, dan pihak berkuasa kerajaan ☐

atau undang-undang, mempunyai akses langsung kepada data bagi memastikan penyelidikan ini dijalankan dengan betul dan data direkodkan dengan betul. Segala maklumat dan data peribadi akan dianggap sebagai **SULIT**.

- Saya faham bahawa petikan tidak bernama daripada temubual mungkin akan digunakan di dalam mana-mana laporan, penerbitan, atau pembentangan hasil daripada projek ini. ☐

- Saya akan menerima satu salinan 'Risalah Maklumat Peserta dan Borang Persetujuan Peserta' yang telah lengkap dengan tarikh dan tandatangan untuk dibawa pulang ke rumah. ☐

- Saya bersetuju untuk mengambil bahagian dalam penyelidikan ini. ☐

Peserta:

Tandatangan: Nombor K/P:

Nama: Tarikh :

Penyelidik yang mengendalikan proses menandatangani borang keizinan:

Tandatangan: Nombor K/P:

Nama: Tarikh :

Appendix 5 : Interview guide

(Introduction)

I would like to thank you for giving me chance to talk to you. My name is Ashikin Atan, and currently I am a PhD in Nursing Studies candidate from the University of Edinburgh. I am also a sponsored student from Ministry of Education, Malaysia. The interview should take less than one hour. Our conversation will be audiotaped so that I will not miss any of provided information. You may also see me taking note during the interview, but that does not mean I am not listening to you as I am writing down some points that require further exploration.

Nobody will be listening to the tapes except for people on the project. I will be reading the transcripts of your interview and transcript of interviews with other people that I have interviewed. I will compare the interviews, make summaries and say this as what goes on. I might quote people, but if I do, I will drop out any of your identifying information.

If at any time during the interview you wish to discontinue the use of the recorder of the interview itself, please feel free to let me know. You may withdraw from this study at any time without any penalty.

I am your responsible researcher, and my research is supervised by two supervisors from The University of Edinburgh, Dr Sarah Rhynas and Professor Tonks Fawcett. You and I both signed and dated each copy of consent form, confirming that we agree to continue this interview. You will receive one copy and I will keep the other under lock and key.

Just to make sure you have understood all information given in the information sheet and your consent to this study is voluntary. If at any time you need to stop, take a break, and please let me know.

Do you have any question or concern before we begin this interview?

Interview guide for T2DM patient

PART A: SOCIODEMOGRAPHIC CHARACTERISTICS

1. Age: _____ year-old

2. Gender:
    a. Male
        [ ]
    b. Female
        [ ]

3. Race:
    a. Malay
        [ ]
    b. Chinese
        [ ]
    c. India
        [ ]
    d. Others
        [ ]

Please specify: _____

4. Religion:
    a. Islam
        [ ]
    b. Hindu
        [ ]
    c. Buddha
        [ ]
    d. Christian
        [ ]
    e. Others
        [ ]

Please specify: _____

5. Occupation: _____

6. Establishment:_____

PART B: HEALTH CONDITION CHARACTERISTICS

1. Duration having diabetes:

_____ months/years

2. Having any other health problems:
    a. Yes

        [ ]

Please specify:

_____

    b. No

        [ ]

3. Having any diabetes complication
    a. Yes

        [ ]

Please specify:

_____

    b. No

        [ ]

PART C: INTERVIEW GUIDE

1. Exploring patients' experience of involvement in the decision-making process
    a. How health decisions on your T2DM were made in the past?
        i. How involved were you?
        ii. How was your feeling/acceptance
        iii. Are you satisfied with the way that the decisions were made?
        iv. Anything that you want to change in the decision-making process or in the overall illness management?

2. Explore the patients' perspectives on patient involvement in decision making in the management of their' illness
    a. What can you understand about patient involvement in decision-making
    b. Do you know about shared decision-making?(if the participant is not familiar with the term – to provide general definition of it)
        i. What is your view about this approach?
        ii. What do you think its' benefits or drawbacks? Why?
        iii. What do you think can be the barriers and facilitators? Why?
    c. Any other concerns

3. Explore patients' preferences of shared decision-making
    a. In your opinion, what is the best way of making management decision for you T2DM?
        i. "I prefer to make the final decision selection about which treatment I received" – autonomous
        ii. "I prefer that my healthcare professionals and I share responsibility for deciding which treatment is best for me" – shared
        iii. "I prefer to leave all decisions regarding my treatment to my healthcare professionals" – paternalistic
    b. Reason for the choice?

4. Explore the patients' expectations of the shared decision-making concept
    a. What do you expect if you are involve in making the decision?

b. How these expectations may relate to your self-efficacy and satisfaction?

Interview guide for HCP

PART A: SOCIODEMOGRAPHIC CHARACTERISTICS

7. Age: _____ year-old

8. Gender:
    a. Male
        [ ]
    b. Female
        [ ]

9. Race:
    a. Malay
        [ ]
    b. Chinese
        [ ]
    c. India
        [ ]
    d. Others
        [ ]

Please specify: _____

10. Religion:
    a. Islam
        [ ]
    b. Hindu
        [ ]
    c. Buddha
        [ ]
    d. Christian
        [ ]
    e. Others
        [ ]

Please specify: _____

11. Occupation: _____

12. Establishment:_____

13. Years of working experience: _____ years

PART B: INTERVIEW GUIDE

1. Exploring HCPs' experience of involvement in the decision-making process
    a. How health decisions on your T2DM patients were made in the past?
        i. How involved were they?
        ii. How was your feeling?
        iii. Are you satisfied with the way that the decisions were made?
        iv. Anything that you want to change in the decision-making process or in the overall illness management?

2. Exploring HCPs' role in the overall management and decision-making in managing T2DM patients
    a. What is your role in the overall management and decision-making in managing T2DM patients?

3. Explore the HCPs' perspectives on patient involvement in decision making in the management of their' illness
    a. What can you understand about patient involvement in decision-making
    b. Do you know about shared decision-making?(if the participant is not familiar with the term – to provide general definition of it)
        i. What is your view about this approach?
        ii. What do you think its' benefits or drawbacks? Why?
        iii. What do you think can be the barriers and facilitators? Why?
    c. Any other concerns?

4. Explore HCPs' preferences of shared decision-making
    a. In your opinion, what is the best way of making management decision for your T2DM patients?
        i. "I prefer to make the final decision selection about which treatment they receive" – paternalistic
        ii. "I prefer that my patients and I share responsibility for deciding which treatment is best for me" – shared
        iii. "I prefer to leave all decisions regarding the patients' treatment to them" – autonomous
    b. Reason for the choice?

5. Explore the HCPs' expectations of the shared decision-making concept
    a. What do you expect if you involve your patients in making the decision?

Appendix 6

Ethical approval from Medical Research and Ethics Committee (MREC)

JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN
(Medical Research & Ethics Committee)
KEMENTERIAN KESIHATAN MALAYSIA
d/a Institut Pengurusan Kesihatan
Jalan Rumah Sakit, Bangsar
59000 KUALA LUMPUR

Tel.: 03-2287 4032/2282 0491/2282 9085
03-2282 9082/2282 1402/2282 1449
Faks: 03-2282 0015

Ruj. Kami : (5) KKM/NIHSEC/P15-1332
Tarikh : 3hb November 2015

ASHIKIN BINTI ATAN
SCHOOL OF HEALTH IN SOCIAL SCIENCE
THE UNIVERSITY OF EDINBURGH

Tuan/Puan,

NMRR-15-1495-26120(IIR)
SHARED DECISION MAKING IN THE MANAGEMENT OF TYPE 2 DIABETES MELLITUS IN MALAYSIA: THE PERSPECTIVE OF PATIENTS AND HEALTHCARE PROFESSIONALS.

Lokasi Kajian: [redacted]

BIL	LOKASI KAJIAN
1	[redacted]
2	
3	
4	

Dengan hormatnya perkara di atas adalah dirujuk.

2. Jawatankuasa Etika & Penyelidikan Perubatan (JEPP), Kementerian Kesihatan Malaysia (KKM) tiada halangan, dari segi etika, ke atas pelaksanaan kajian tersebut. JEPP mengambil maklum bahawa kajian tersebut hanya melibatkan pengumpulan data menggunakan **kaedah temubual** sahaja.

3. Segala rekod dan data subjek adalah **SULIT** dan hanya digunakan untuk tujuan kajian ini dan semua isu serta prosedur mengenai *data confidentiality* mesti dipatuhi. Kebenaran daripada Pegawai Kesihatan Daerah/Pengarah Hospital dan Ketua-Ketua Jabatan atau pegawai yang bertanggung jawab disetiap lokasi kajian di mana kajian akan dijalankan mesti diperolehi sebelum kajian dijalankan. Tuan/Puan perlu akur dan mematuhi keputusan tersebut.

4. Adalah dimaklumkan bahawa kelulusan ini adalah sah sehingga **2hb November 2016**. Tuan/Puan perlu menghantar dokumen-dokumen seperti berikut selepas mendapat kelulusan etika . Borang-borang berkaitan boleh dimuat turun daripada laman web MREC (http://www.nih.gov.my/mrec).

I. *'Continuing Review Form'* selewat-lewatnya 2 bulan sebelum tamat tempoh kelulusan ini bagi memperbaharui kelulusan etika.
II. Laporan tamat kajian pada penghujung kajian.

III. Laporan mengenai *"All adverse events, both serious and unexpected"/Protocol Deviation* atau *Violation* kepada Jawatankuasa Etika & Penyelidikan Perubatan, KKM jika berkenaan.

IV. Memaklumkan jika terdapat pindaan keatas sebarang dokumen kajian.

5. Sila ambil maklum bahawa sebarang urusan surat-menyurat berkaitan dengan penyelidikan ini haruslah dinyatakan nombor rujukan surat ini untuk melicinkan urusan yang berkaitan.

Sekian terima kasih.

BERKHIDMAT UNTUK NEGARA

Saya yang menurut perintah,

(DATO' DR. CHANG KIAN MENG)
Pengerusi
Jawatankuasa Etika & Penyelidikan Perubatan
Kementerian Kesihatan Malaysia

CC

Pengarah
[redacted]

Pusat Penyelidikan Klinikal
[redacted]

Pengarah
[redacted]

Pusat Penyelidikan Klinikal
[redacted]

Pegawai Kesihatan
[redacted]

Pegawai Kesihatan
[redacted]